UNIVERSITY of ALBERTA

AN ETHNOGRAPHY OF FAMLIES WHEN A CHILD HAS DIED

By

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©

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ABSTRACT

Although the death of a child today is a relatively uncommon experience, significant social costs, including increased mortality, morbidity, and financial strains are experienced. To date grief and mourning have been most commonly considered as phenomena that lie within the fuctioning of the individual. Little is known about the experience of families during bereavement.

This focused ethnography examined family mourning using two units of analysis. Thirteen families and thirty-four individuals were interviewed to develop an understanding of the culture of families who have experienced the death of their child.

Results indicated that parallel processes occur for the individual family member and for some families as a social group during bereavement in which they experienced grief, mourning, and reformulating/restructuring. While some families are able to work together in a shared process during bereavement, others cannot. As well, families form a context of support for the individual process. For both individuals and families there are characteristics that influence this process, termed antecedents. For the individual these are their attitudes, beliefs, and patterns of coping. For families these are their norms, and roles, and routines. For some families these antecedents appear to preclude shared family work. When family serves as context for the individual process during bereavement, family members support one another by creating space for differences in individual patterns of grieving and mourning. Family members also engage in "loving acts" and "kindness acts" in order to aid the family members in their individual process and assist the family to restructure through creating a place for the spirit of the child, and through the creation of new routines and roles. This process during bereavement following the loss of a child has been conceptualized as family work.

DEDICATION

This dissertation is dedicated to the memory of my daughter, Jessica Kelly, whose spirit lives on in my heart and in our family. Her life taught me how to be a mom, her dying taught me what it means to be courageous, and her death taught me what it means to live.

Additionally, I wish to dedicate this dissertation to families—by blood, marriage, adoption, and choice—those who support us, give us strength, and teach us all of life's valuable lessons. To my father, Reidar Berg, who always believed in me. To my mother, Beatrice Berg, who taught me the importance of continual learning. To my husband, Jan deJong, who taught me what it is to be cherished. And especially to those families whose members so graciously agreed to take part in this study. They are a source of inspiration to me.

Finally, I dedicate this work to the children who died. Ultimately, they are the reason why this dissertation had to be written.

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Just like bereavement, the journey of a Ph.D. dissertation is best traveled in the company of supportive people who are there to share your ups and downs. It is this "family" with its many and varied members that I would like to acknowledge.

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Second, but no less important to acknowledge, is the role my family played in this story of family grief and mourning. My family has many parts, coming together through birth, adoption, marriage, and choice. We have often been a grieving family, struggling at times in our mourning. Family began for me in the nurturing environment created by my parents, Reidar and Beatrice Berg; this nurturing was sustained by my "full nest" of siblings: Rita and George Cornille, Bobbie and John Bade, Jack Berg, Don and Ann Berg, Tom and Mary Ann Berg, Mary and Tony Scavo, Bill and Linda Berg. Although geographical space created distance and struggles to understand each other at times, particularly in our moments of grief, my siblings have taught me that family can be relied on always -- through dark days and bright, shining moments. They have taught me what it is to be protected, supported, and loved.

My family extends to my children who arrived through various means but who have all added a joy to my life, creating a fuller life filled with love. I would like to acknowledge the support of my children: my son, Robert Kelly -- always the bright spot of my life, providing joy even at moments when it could have been easily lost--who together with his wife Sarah continue the cycle of family; my daughter, Maria Kelly -- a brave soul who knows grief and rises above it on a daily basis; my son, Michael deJong -- a special addition to my life who teaches me to get on with life and together with his wife Angela looks to hope and a bright future; and my son, Robert deJong -- a man of compassion, who has risen above his own grief to teach a lesson of acceptance and love. My family has been blessed with beautiful grandchildren, Elizabeth, Margaret, Declan, Breanne, and Matthew. They are a source of renewal and fill my life with laughter and meaning as I watch them grow.

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CHAPTER 1

INTRODUCTION

Families who experience the loss of a child most commonly describe their worlds as "shattered" and their lives as never again the same (Malkinson & Bar-tur, 2004-05; Rando, 1986; Rosenblatt, 2000, Wheeler, 2001). Routines may be disturbed and social contacts may be disrupted, leaving family members feeling out of place within their social networks. Spouses may not know how to approach each other and surviving siblings of the deceased child may experience intense loneliness not only in terms of the loss of their sibling, but in terms of the unavailability of their parents (Davies, 1999; Riches & Dawson, 2000). Grief theorists maintain that grief experienced following the death of a child is always complicated, involving a longer duration and greater intensity of symptoms than do other grief responses (Rando, 1993; Rubin & Malkinson, 2001).

Compared to the situation at the beginning of the 20th century, the death of a child today is uncommon. Nonetheless, Finkbeiner (1996) has suggested that 1 family in 19 is affected by the death of a child. In Canada in 2004 (the latest year of published statistics), the deaths of 3449 children ages 0 to 19 were recorded (Government of Canada, 2004). Rando (1993) suggested that an estimated 8 to 10 family members are affected by each child's death, leaving many people adjusting to this event and the grief it brings.

Numerous social costs related to the phenomenon of losing a child are reported in the literature: increased rates of mortality (Li, Pretch, Mortensen, & Olsen, 2003); pyschiatric admissions (Li, Laursen, Precht, Olsen, & Mortensen 2005); and marital breakdowns (Warren, 1997). Further, financial and social costs may be experienced by families due to increased rates of drug or alcohol abuse and accidents, all resulting in the need for greater health care services. Financial costs also include funeral expenses, repayment of debt incurred while caring for the sick child, and income reduction due to employment difficulties of parents (e.g. difficulties returning to the workplace and lost opportunities for advancement) (James & Friedman, 2003; Rando, 1993). As well, the parents' workplaces are affected through increased absenteeism, lost productivity, and reduced quality of work (Rando, 1993). The Grief Recovery Institute in the United States (James & Friedman, 2003) estimated the cost of lost American workplace productivity per year due to the death of a loved one as $37.5 billion. Workplace productivity statistics specific to the death of a child have not been reported.

Societal norms may present barriers to assisting family members in dealing with their grief (Walter, 1999). While parents are recognized as the "legitimate" grievers, the grief experienced by the siblings of the deceased child may go unrecognized. Often these young family members are encouraged to "take care of their parents". These well-intentioned words inadvertantly deny siblngs' own needs for support (Hogan & DeSantis, 1994). Grandparents are often looked on as a source of family support without the recognition that they too grieve (Galinsky, 2001). The grief of other family members such as aunts, uncles, and cousins has not yet been reported in the literature. In her classic work on grief and dying, Rando (1984) suggested that North American society is death denying. As a result, displays and discussion of grief are restricted to a six week to three month period after the death of a family member. Thereafter, many families are left without the social and environmental resources needed to cope with their loss over the lengthy time needed for mourning when a child dies. Indeed, bereavement leave from the workplace in Canada is most often restricted from 3-5 days, when offered at all (Government of Canada, 2005).

This study was undertaken to begin to address the gaps in knowledge specific to the death of a child,. In particular, the purpose of this study was to investigate the experiences of families when a child has died.

Focus of the Study

Two Units of Analysis

To date, bereavement has been studied primarily from an individual perspective and little is known about how families as a collective mourn the death of a child. There is very little published research about grief and mourning in which family is the unit of analysis. Shapiro (1996) suggested that the lack of studies conducted about family grief may be due to the widely held assumption that grief is fundamentally a private experience. Further, Moos (1995) reported that while a death in the family has been acknowledged to affect the functioning of the family as a unit, grief researchers have most often addressed only the experiences of individual family members and have rarely investigated grief as a family process. To understand the family experience during bereavement requires an examination of the phenomenon at both individual and family levels; but to do so is a complex undertaking. Each family of a child who has died is made up of individuals who are experiencing their own personal grief issues. As well, interactions among family members and transactions of families with larger systems such as the community and society influence the experience of individuals as well as the family collective during bereavement. While understanding the larger community and societal context during bereavement is important, this study is limited to an examination of the experiences of the individual and family, and the interactions among family members in the family unit during bereavement of a child. Thus, in this research study, two units of analysis were examined—the experiences of individuals and families during bereavement for child.

Grief, Mourning, and Bereavement

Initially, in conceptualizing this study, I focused on the family experience of mourning following the death of a child, and on the interrelationships between family mourning and the individual experiences of grief of family members. To do so, I relied on commonly accepted definitions from the literature, including them as working definitions. Grief was defined as "a primarily emotional (affective) reaction to the loss of a loved one through death" (Stroebe, Hansson, Stroebe, & Schut, 2001, p. 6) as well as the cognitive experiences of the individual (Worden, 1982). The working definition of mourning was "the social expressions or acts expressive of grief that are shaped by the practices of a given society or cultural group" (Stroebe et al., 2001, p. 6), and as a range of behaviors encompassing the outer display of the inner experience of grief often seen in the use of culturally based rituals and traditions (Archer, 1999). The working definition of bereavement was "the objective situation of having lost someone significant" (Stroebe et al., 2001, p. 6) and a state of having experienced a serious loss, with the term often used to signify the time period of mourning and grief (Rando, 1993; Sanders, 1999). During the course of the study I recognized that the experiences of families and individuals following the death of a child involved an ongoing process including grief, mourning, and adjustment necessitating a change in conceptualization and a modification of the title to include the concept of "Family Bereavement" to more accurately capture the entire experience of family after the death of a child, thereby reflecting the changes families (and individuals) undergo over time.

Ethnographic Approach to Explore Family Experience

When individuals come together as family they form a group. This group must construct a meaning of their shared experiences in both shared and individual processes

(Daly, 1992). Family is the basic unit of any society (Badir, 1993), bridging the gap between the individual and the social and economic groups within which the individual interacts. Family can be defined as both a cultural and economic construct. As a cultural construct, families have rules of formation, follow traditions, and engage in rituals and celebrations that are influenced by the societal norms (Badir, 1993). The patterns of relationships among family members and the ways families spend time together are rooted in the economic conditions of the larger society. While these larger societal ~~conditions~~ are important in bereavement, they were not explored in this study which focused on the interactions between family members and the transaction within family.

In order to examine these interactions and transactions a qualitative approach was used; specifically a focused ethnography was conducted. A qualitative approach to family research provides an opportunity for the researcher to examine the richness and complexity of family life and is particularly appropriate when studying family systems phenomena and family dynamics. These phenomena and dynamics can include the congruence and incongruence of multiple family members' viewpoints, and theoretical questions about the meanings, understandings, and perceptions of family members. Family research using a qualitative approach assumes that family is the focus of analysis. Critical data lie in the meanings family members make of their behaviors, feelings, and thinking about and within their family, and the details and idiosyncrasies of what individuals communicate about their family (Rosenblatt & Fischer, 1993). Focused ethnography is a suitable method to seek an understanding of the culture of families who have experienced the death of a child. Focused ethnography is particularly appropriate because it allows the researcher to examine the stories of various participants for the patterns within these accounts in order to create an understanding of the whole of their experience as a cultural group (Agar, 1980).

Defining Family

While numerous definitions exist in the literature; for the purpose of this study, family was defined as: "a system of two or more interacting persons who are either related by ties of marriage, birth, or adoption, or who have chosen to commit themselves in unity for the common purpose of promoting the physical, mental, emotional, social, economic, cultural, and spiritual growth and development of the unit and each of its members" (Yuen, 2005, p. 1). This definition is sufficiently broad to allow participants to define membership in their family. While not being limited to only those members who live in the household, this definition allowed membership to extend to all those who played a critical role in the family unit. This definition is one of the few identified in the literature that also included the important dimension of spirituality reported to be critical in family bereavement (Rosenblatt, 2000).

Researcher's Assumptions

The Role of My Experience in Formulating the Study

While to date most studies of bereavement focus only on the individual experience, my experience as a bereavement counselor over many years and most recently in pediatric palliative care led to my interest in the family's experience following the death of a child. It also led me to question my belief that grief is intensely personal. While my clinical experience was that grievers rarely came to a clinical setting as couples or families, women (who made up the majority of my clients) came to counseling not only because of their own needs but also to get suggestions about how to help their family. It appeared that family members were reluctant to share their deep sadness with one another for fear of making another's grief greater. These clients described their sense of isolation, a feeling that no one understood them or wanted to listen to them. But as clients told their stories I came to believe that individuals were affected by their families and, in turn, influenced the experiences of their families.

My own experience as a mother who has lived through the death of a child reinforced this belief. While my experience of family support during bereavement was negative, I believed and maintained hope that this did not need to be so and that some families "held the key" that could form the basis for interventions that have not yet been utilized in bereavement counseling. To better understand the interface between individual experiences during bereavement and those of the family unit, I needed to explore both constituents.

My Knowledge Paradigm

In using qualitative research approaches it is considered important for researchers to state their beliefs about how knowledge is created (Hammersley & Atkinson, 1995). I believed that the inner experience of grief was real—family members, particularly parents, have reported that the pain they feel is so real that their bodies, minds, and very souls ache (Talbot, 2002; Finkbeiner, 1996) and perhaps these 'symptoms' of grief can be measured. However, I also believed that in order to understand family bereavement I needed to accept that the 'reality' of their experiences would vary for each family member because their relationships with the child were unique. In seeking to understand how family members worked together to understand the loss, reassign roles, adjust family norms, and create a place for the child that contributed to their process of grief and mourning, I believed that multiple and subjective realities existed and that the experiences of families during bereavement were socially constructed. Constructivism suggests that the 'knower' builds knowledge based on individual experience and/or social interaction, independent of an 'external reality' (Heylighen, 1993). For this study on family bereavement, I subscribed to this knowledge paradigm.

The Need for Reflexivity

Reflexivity, a term that refers to "the process of critical self-reflection on one's biases, theoretical predispositions, preferences, and so forth" (Schwandt, 2001, p. 224) required further examination of my biases and assumptions. My biases from clinical practice that required examination for this research study were:

a) I favored a grief work model with a focus on verbal expressions of grief and could have overlooked the less emotionally expressed experiences of family members (Martin & Doka, 2000).

b) Being familiar with the stories of women, I could have given too much or too little emphasis to their perspectives.

c) In my belief that grief was intensely personal, I could have lost my focus on family interactions within the family interview, and could thus have created a series of personal interviews in a family setting, rather than a family interview.

d) My education in social work influenced my knowledge of family systems, social networks, and social policy. Words like function, coping, and process are abundant in my vocabulary.

e) Although I was well versed in conducting the clinical interview, I had less expertise with the research interview and needed to maintain a research stance while meeting my ethical obligations as a professional social worker.

As a researcher, I benefited from my clinical experience in that I was not afraid to hear the pain of grief and mourning. To safeguard against my biases I maintained methodological and reflective field notes and reviewed these in supervisory sessions. I included an assessment of my role as research interviewer and a review of coding and categorizing decisions so that my description of family process during bereavement was derived from the data and not from my previously held knowledge and biases. Further, I underwent an individual and family interview and these interviews (with an assigned pseudonym) are included as study data.

Purpose of the Study

The purpose of this study was to describe and understand the family experience during bereavement following the death of a child. Families needed to define for themselves who constituted family, taking into consideration the contributions of members holding various relationships within the family. In so doing, new insights could be gained about the work families do during bereavement and the various ways they support one another at this time. When family is interviewed as a group, transactions among members can reveal data that are not available from individual interviews, and thus can afford additional insights into the conceptualization of experiences during bereavement (Rosenblatt & Fischer, 1993).

To understand how family roles, norms, values, and patterns of behavior were affected during bereavement, a wide range of family types was sought. These types included nuclear, extended, divorced, and remarried families. Some families held shared beliefs on the way the family was to function, ranging from strictly held religious beliefs to more moderate views. Other families held divergent beliefs among their family members. In order to gain further insight into the experience of families during bereavement individual family members were interviewed alone to understand their personal experiences during bereavement following the death of a child, especially to understand how they perceived themselves to influence and be influenced by the family's experience. Family members included parents, brothers/sisters, grandmothers, aunts and uncles (including family of choice members). All grandfathers within the families declined to be interviewed. Interviewing individuals and families allowed an exploration of how family members differentiated between individual experiences during bereavement and those of the family as a unit.

While an original objective of the study was to examine how family members differentiated among the terms grief, mourning, and bereavement it appeared that they were unable to do so, perhaps because in the midst of the experience these distinctions become irrelevant or that the inner and outer experiences are so intertwined that one cannot distinguish one from the other. It is important to note bereaved parents do not have a label such as widow/er and orphan that may afford family members the learning of how to fulfill a social role as one of the bereaved.

This dissertation is comprised of seven chapters. Following this introduction, in Chapter 2, I will address the conceptual framework that formed the basis for my initial understanding of the experience of families during bereavement, including the sensitizing concepts of role, norm, interaction, communication, resources, appraisal, and adaptation. In Chapter 3, I will briefly discuss issues in family research and review the bereavement literature from both the perspective of family and the individual family members. In Chapter 4, I will discuss the design and procedures of my study, addressing in particular, the changes that occurred over the course of the study as data were collected and analyzed. In Chapter 5, I present the first of two chapters of findings of my study. This chapter is comprised of the family stories (within case analysis) of each family in the study. In Chapter 6, I present the themes resulting from the analysis of the family and family member data (across case analysis). Finally in Chapter 7, I discuss the key findings from within the context of the empirical and theoretical literature.

CHAPTER 2

CONCEPTUAL FRAMEWORK

A conceptual framework formed the philosophical basis and provided a focus or "lens" for the inquiry (Morse & Richards, 2002, p. 171). In this study of family bereavement, with both the individual and family as units of analysis, it was appropriate to construct a conceptual framework that supported the focus on each unit as well as on the interaction between these units. In order to do so, various lenses were needed to supply the sensitizing concepts required to inform my understanding and to provide a beginning framework for viewing family bereavement following the death of a child. Sensitizing concepts are starting points not meant to constrain the inquiry, and tentative in that they helped me understand what was going on. During analysis I continually questioned "Do they fit?" and, "How might the phenomenon be different or the same to that conceptualized from these sensitizing perspectives?" I anticipated that as the research progressed and my emic understanding of the families' experiences grow, I would challenge and question the usefulness of the sensitizing concepts as a way to frame my analysis. And indeed this occurred as the concepts presented In the Dual Process Model of Bereavement were replaced by those from Morse and colleagues (1996, 1999, 2001, 2005, 2007) Theory of Enduring, Suffering, and Reformulating Self as will be further discussed in Chapter 6.

Theoretical Perspectives

The three theoretical perspectives that informed the study at its inception were Symbolic Interactionism (Charon, 1985), Stress and Coping Theory (in particular the double ABCX model proposed by McCubbin and Patterson in 1983), and the Dual Process Model of Bereavement (Stroebe & Schut, 1999). In Table 1.0 the sensitizing concepts used to inform this study are presented.

Table 1

Sensitizing Concepts and Definitions

Symbolic Interactionism

Concept	**Definition**
Identity	"...the stable, consistent, and reliable sense of who one is and what one stands for as a contributing member of society" (Fullinwider & Jacobvitz, 1993, p. 87)
Role	Behavioral expectations learned in childhood as the child practices the behaviors observed in others (Goffman, 1961).
Boundaries	Demarcation between self and others (Jordan, 1991)
Norms (family rules)	A working consensus that includes patterns of separateness and connectedness in the form of internal and external boundaries (LaRossa & Reitzes, 1993)
Communication	"social interchanges between individuals and groups" (Eshleman & Wilson, 1994, p. 55)
Interaction	The mutual social actions of individuals (Charon, 1985).

Family Stress and Coping

Concept	**Definition**
Resources	"the capabilities and strengths that prevent an event or a transition from creating a crisis" (McCubbin & McCubbin, 1987).
Perception of threat/appraisal	The way the family perceives the event (Hill, 1958).
Time	A system for organizing the chronology of events into past, present and future; the dimension along which family processes occur.
Pile-up	Experience of multiple stressors over time (McCubbin & Patterson, 1983)
Adaptation	"the family's efforts to achiheve a balance in functioning" (McCubbin & Patterson, 1983, p. 101).
Coping (family)	The strategies and behaviors the family uses to maintain its emotional stability and well-being (McCubbin & McCubbin, 1987).

Table 1

Sensitizing Concepts and Definitions (continued)

Family Stress and Coping

Concept	**Definition**
Coping (individual)	"constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are praised as tasing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141)

Dual Process Model of Bereavement

Concept	**Definition**
Loss-orientation	Behaviors following a death that include grief work, the intrusion of grief, breaking bonds/ties/relocation, and denial/avoidance (Stroebe & Schut, 1999)
Restoration-orientation	Attending to life changes, doing new things, distraction from grief, denial/avoidance of grief, new roles/identities/relationships (Stroebe & Schut, 1999).
Oscillation	Waxing and waning of grief and mourning (Stroebe & Schut, 1999)

Symbolic Interactionism

The "grand" theory of Symbolic Interactionism is useful for understanding the behaviors of the individual and the interplay among family members. The theory is based on the emphasis of humans constructing symbols, especially within language, to create understanding and meaning for their behaviour and through interaction, defining and redefining their perspectives (Charon, 1985; LaRossa & Reitzes 1993). While Symbolic Interactionism has led to the development of many important concepts that aid our understanding of the behavior of individuals and families, the specific sensitizing concepts used in this study included identity, role, norm (family rules), boundaries, communication, and interaction.

Concepts for Viewing Individual Behaviors

The interrelated concepts of identity, role, and norm, essential characteristics of the theory are crucial to understanding individual social acts and the individual's relationships with family members (Fawcett, 1989). The sensitizing concepts of interaction and communication gave me an important starting point for examining the behaviours of family members in concert with one another as they experienced the death of their child.

Identity. Identity requires the individual to examine self from three views: a) the individual self - the unique set of attributes one possesses; b) the relational self - composed of those attributes shared with significant others and incorporated into self through an assimilation process and formation of attachment bonds; and c) the collective self - a constellation of attributes shared with an 'in group', distinct from those of an 'out group' (Sedikides, 2002). Family may constrain or enhance the formation of identity by providing an environment where the individual works to balance autonomy and closeness through maintaining an emotional bond and providing a sense of connectedness (Fullinwider & Jacobvitz, 1993). However, one must decide where 'I' begins and ends apart from the perceptions of others.

Boundaries. Boundaries allow for the distinction between the self and others. During adolescence, young people must wrestle with the definition of self that has been provided by others, particularly family, and seek out confirmation within themselves as to who they are and who they will become (Jordan, 1991). Identity and a healthy sense of self are developed by internalizing role expectations of family and the greater society (McCall, 2003).

Role. Role is a concept that has spawned a theory with multiple variations. Roles, the expected behaviors of incumbents of positions (such as mother, father, sibling), are defined by the norms of a given society and culture. Roles allow the role incumbent and others to anticipate future behaviors. They also provide regularity in social interactions (LaRossa & Reitzes 1993). Roles are said "...to reflect the norms, attitudes, contextual demands, negotiation, and the evolving definition of the situation as understood by the actors" (Biddle, 1985, p.71). An individual may occupy many roles simultaneously and together these roles contribute to identity. Individuals may struggle with fulfilling their many roles leading to role conflict. For individuals who have experienced the death of a child, roles may be disrupted and their very sense of identity threatened, especially when they no longer occupy a social position as parent or sibling (Rando, 1986; Talbot, 2002). The concepts of identity, role, and boundaries are closely linked to those that provide an understanding of how the individual functions within the family group.

Concepts for Viewing Interactions In Families

Achieving an understanding of the behaviors of family members as they relate to one another during bereavement can be aided by the use of the sensitizing concepts of norms (family rules), interaction, and communication.

Norms. Families establish their own norms (more commonly referred to as rules) that can be tacit or explicit. Rules maintain family stability requiring a family member to account for behaviors that do not fit with what is expected, thereby restoring meaningful interactions within problematic situations for the family (LaRossa & Reitzes 1993).

Interactions. Family rules guide interactions between individuals, particularly within families, influencing the development of self and identity as well as the way a role is taken on (Charon, 1985).

Communication. Interaction includes communication. Within the theory of Symbolic Interactionism, communication is much more than simply sending messages verbally and nonverbally. It is a way human beings achieve collective meaning of the situation (Charon, 1985). Through telling each other their stories of the child, family members can make sense of the child's death and create meaning from the experience. In the process of communicating with each other, family members' shared experiences can allow them to work together as a group.

As a human being, the individual views the world from an ever-changing, interpretive and experiential stance rather than reacting to the 'facts' of the situation (Rock, 2001). He/she thinks about him/herself, and combines these thoughts with the reactions of others prior to taking action. Behaviors are the outward display of the inner interpretations of reality. An important component within Symbolic Interactionism is the Thomas axiom—when people define situations as real, they are real in their consequences (Rock, 2001). Family communication patterns and language, a system of significant symbols, becomes a way for family members to share meaning.

Symbolic Interactionism unites cultural meanings with social behaviors. The current study explored the behavior of families during bereavement, with the goal of creating a description of the culture of families following the death of a child. As individuals contribute to the meaning of a family's situation, behaviors can became organized and lead to adaptation (Stryker, 1959; White & Klein, 2002).

Family Stress and Coping Theories

While Symbolic Interactionism is useful for understanding individual behaviors and the interactions of family members, Family Stress and Coping Theories offered additional concepts that were useful in further understanding the behaviors of bereaved families in terms of their adaptation on a family level. Family Stress and Coping Theories, rooted in the work of Hill's ABCX Family Crisis Model (1958), introduced the concepts of stress, resources, coping, and appraisal, perception, or definition of the event, which aided my understanding at the family level of analysis. As well, these concepts provided a further means to view interactions between family members. Specifically the family theory proposed by McCubbin and Patterson (1983), the Double ABCX Model, addressed the aforementioned concepts and contributed the additional sensitizing concepts of time, pile-up, and adaptation that helped focus understanding of family behaviors during bereavement. These additional sensitizing concepts were useful to this examination of family bereavement.

Resources and perception of threat. Hill (1958) suggested two concepts; resources and definition of the event, renamed by McCubbin and Patterson (1983) perception of threat, which can be important in examining a crisis such as the death of a child. Hill postulated that an event in the life of the family will be evaluated as a crisis depending on the resources available to the family and their perception of threat in the event. The first concept, resources can include both internal resources such as the ability to provide emotional support to each other and external resources such as financial benefits from employment. The second concept, perception of threat, suggests that how family members perceive the stressor is more important than how it is defined by the outside world. It is closely associated to the symbolic interactionist concept of meaning. For the purposes of this study, perception of threat provided a means to view the initial reactions of families to the death of a child.

Pile up and time. McCubbin and Patterson (1983) added important extensions to Hill's theory. One of these, Pile up, affects a families' ability to meet the demands of the most current stressor (Braithwaite & Baxter, 2006). A family may already be experiencing other life events that affect them during bereavement. Time, during which the everyday events of families occuring over time creates a mutual history and ties between family members, is a critical element in bereavement (Daly & Beaton, 2005). Family events encompass not only day-by-day activities but the rituals marking special events such as births, holidays, and death (Rando, 1984). Time allows the process of grief to unfold and allows family to cope.

Coping. Coping includes the use of resources from both within the family and the community (McCubbin & McCubbin, 1987). It is affected by a family's resources which exist at the time of the child's death as well as by new resources. These new resources may be developed in response to a perception of crisis and the concomitant coping needed over time in consideration of the pile-up of other stressors in their environment. Coping is not stressor specifically, but a more global set of family behaviors developed over time in response to multiple events of stress leading to family adaptation (McCubbin & McCubbin).

Adaptation. The result of family members' coping abilities is adaptation. Over time adaptation to the stressor or crisis can occur which can lead to either a balanced family functioning (bonadaptation) or dysfunction (maladaptation) (McCubbin & Patterson, 1983). Including both aspects of adaptation as well as the concept of time, McCubbin and Patterson (1983) suggested that adaptation was a process that occured over time that can be positive or negative to family functioning and the handling of the crisis.

Dual Process Model of Bereavement

Further sensitizing concepts for understanding individual grief are introduced in the Dual Process Model of Bereavement by Stroebe & Schut (1999). They proposed that in order to understand the coping that is required in the grief process, both ***loss-oriented*** *and* ***restoration-oriented*** activities need to be considered. Stroebe & Schut suggested that the grieving individual will ***oscillate*** between confronting and avoiding his/her feelings of grief and tasks of mourning. Further, they suggested that interactions with others affected the grieving process of an individual. The discordance in the expression of distress among family members will affect relationships, well-being, and the coping of both the individual and family. Stroebe and Schut suggested possible outcomes during bereavement which included "positive growth", emergence of different roles and identities, and restored functioning of the family as a unit when relationship maintenance occurs. They further suggested that it is expected that emotions and behaviors of family members will vary with each observation of the family and the individual.

Together the three theoretical perspectives of Symbolic Interactionism, Family Stress And Coping Theories, and the Dual Process Model of Bereavement address the important issues of context, changes through time, and behaviors observed in individuals and families that have been found in the literature to be important to the study of grief and mourning. These sensitizing concepts form the framework for this study on family bereavement.

CHAPTER 3
REVIEW OF THE LITERATURE

In this chapter I will review the literature that informed the study including: a) a brief overview of the issues in grief, mourning, and bereavement, b) pertinent issues in studying family, and c) reviews of the empirical literature addressing the issue of bereavement following the death of a child. Further, this review identifies the gaps that this study proposed to address. Due to the methodological and practical challenges when the family is the unit of analysis, most studies conducted on grief and mourning when a child dies focus on the experience of parents or siblings with few seen where family was the unit of analysis. A search of the Family and Society Studies Worldwide database, in consultation with the University of Alberta Human Ecology librarian, using the search terms grief/mourning/bereavement and family and death of child produced 68 articles, none of which were empirical studies with family as the unit of analysis. Searching the Ovid database produced the 7 empirical studies reported on in this literature review. Further contributions to our knowledge on the phenomenon of family bereavement are found in the theoretical literature and that from clinical practice, most notably in the family therapy literature. This literature review will focus on the empirical literature but also identify contributions from the theoretical and clinical literature when relevant.

Grief, Mourning, and Bereavement

Defining the Terms

Human beings react to loss. Occurring across cultures, this reaction is most commonly referred to as grief (Christ, Bonanno, Malkinson, & Rubin, 2002), but in the English language three words —grief, mourning, and bereavement— are used, often interchangeably, to describe this experience (Cowles, 2000). In this study, participants were asked to define the terms grief, mourning, and bereavement in their own words in order to further understand their experience of the death of their child. While in the professional literature, the terms grief, mourning, and bereavement are used with some consistency, it is not known if this consistency occurs in the general public. However, working definitions are needed as a starting point for discussion in this document.

In both the research and clinical literature, 'grief' is most often used to describe the inner experience of the individual; that is the feelings and thoughts that result from the loss. In their concept analysis of grief as found in the professional literature, Cowles and Rogers (1991) define grief as a dynamic, pervasive, highly individualized process with a strong normative component. However, the majority of articles selected in this analysis had been authored by people of Anglo heritage. To investigate this concept further, Cowles (1996) conducted another study, using focus group methods and drawing on a culturally diverse population, to arrive at a culturally inclusive definition of grief from participants' own experience. Only one distinction among the participant group arose; participants made no mention of grief as normative. Cowles and Rogers (1991) further examined the use of the term mourning in the professional literature and found that when distinctions were made between 'grief' and 'mourning', 'mourning' referred to the rituals and behaviors associated with grief. They also found that mourning behaviors were rooted in cultural variations. No concept analyses were found for the terms mourning or bereavement

For the purpose of this study, the working definition of grief will be "a primarily emotional (affective) reaction to the loss of a loved one through death" (Stroebe et al., 2001,p.6) as well as the cognitive experiences of the individual. The "normal" grief response is thought to encompass a broad range of feelings including sadness, anger, guilt, anxiety, loneliness, fatigue, helplessness, shock, yearning, and at times relief (Parkes, 1975). Cognitive manifestations, such as impairment in memory and concentration, lowered self-esteem and self-reproach, and preoccupation with thoughts of the deceased are thought to be common grief responses as well (Worden, 1982). The great variation seen in the individual grief experience is said to be influenced by the nature of the relationship between the griever and the deceased person (Rando, 1984; Worden, 1991; Moorey, 1995; Stoebe et al., 2001).

The working definition of mourning in this study will be "the social expressions or acts expressive of grief that are shaped by the practices of a given society or cultural group" (Stoebe et al., 2001, p.6). Mourning is said to consist of a range of behaviors including sleep and appetite disturbances, absent-mindedness, social withdrawal, dreams of the deceased person, crying, sighing, over-activity, and avoiding or treasuring reminders of the deceased (Archer, 1999). Mourning is the outer display of the inner experience of grief often seen in the use of culturally based rituals and traditions. Stroebe et al. (2001) stress that when observing and studying mourning it is essential to consider the societal or cultural basis of these displays of grief as these norms greatly influence our definition of "normal" grief and mourning. For the purpose of this study grief will be considered an intrapersonal experience, while mourning will address the interpersonal responses to loss.

Bereavement, as a working definition, will be defined as "the objective situation of having lost someone significant"(Stroebe et al., 2001, p.6). Further, it is a state of having experienced a serious loss, with the term often used to signify the time period of mourning and grief (Rando, 1993; Sanders, 1999). There has been considerable discussion in the clinical literature about the length of bereavement, particularly following the death of a child, but no consensus has been reached. Rando (1984) reported that the empirical literature of the time of her writing suggested bereavement can range from eighteen months to three years in the deaths of adults. However, she found in her dissertation research that following the death of a child, bereavement extends for a much longer time (Rando, 1980). McClowry, Davies, May, Kulenkamp, and Martinson (1987) suggested that actively mourning the death of a child can occur for up to nine years. Malkinson and Bar Tur (2004-2005), on the other hand, stated that bereavement following the loss of child never ends.

However long bereavement lasts, there is agreement that bereavement is a time of intense and time-consuming work. Klass (1996) suggests that during bereavement, parents must transform their bond with their deceased child. In their own words, "The end of grief is not severing the bond with a dead child, but integrating the child into the parent's life in a different way than when the child was alive" (p. 214).

The Current State of Bereavement Theory

Throughout the last century studies on grief and mourning have extended our knowledge on these phenomena resulting in some major shifts in the theory. Two shifts—the understanding of the role of continuing bonds versus detachment, and the importance of doing "grief work"—were particularly relevant when observing the experiences of families. Nadeau (1998) found in her study of families making meaning of the death of an adult member that family members influenced one another in the construction of meaning of the death. It may be that family members influence one another in the formation of the continuing bond with the deceased child. As well, the beliefs of professionals as discussed in the public press may influence the expression of grief within families. To provide an understanding of the current state of the theory, as it pertains to the individual experience of grief and possible insight into the limited view of the phenomena of grief and mourning as a family experience, a brief summary of these changes and grief models will be provided.

Continuing Bond Versus Detachment

Many researchers and clinicians, including John Bowlby, Colin Murray Parkes, and Elizabeth Kubler-Ross, have studied and refined our knowledge of grief and bereavement leading to an understanding of grief as a normal and universal reaction to loss. Based on Freud's seminal work in 1917/1953, "Mourning and Melancholy", and continuing in 1944 with Lindemann's classic paper on grief, "The Symptomatology and Management of Acute Grief", theorists spoke of the need to detach from the deceased person (Klass, 1996). In an effort to define the normal grieving process and design helpful interventions, clinicians emphasized the need to say goodbye and bring closure to the relationship, a process thought to be accomplished on an individual level (Parkes, 1975; Worden, 1982). Failure to do this in a timely manner (within 3 months to one year) was thought to complicate grief and became defined as pathological grief (Rando, 1993). However, other theorists and clinicians began to question this theory with some suggesting that: "Bereavement is not an illness that can be cured. It is a situational adjustment to a loss that may take a lifetime of work" (Taylor, DeFrain, & Ernst, 1986, p.161).

In the 1990s, a significant paradigm shift took place as theorists began to take another look at the experience of grief and found that bereaved persons reported the need for continued bonds with their deceased loved ones (Borner, 2003). Research findings suggested that bereaved persons transformed their pre-death relationship into a new, ongoing one after death, resulting in the formation of a continuing bond (Klass, 1996). This bond was found to be rooted in the individual's memories of the deceased person and in the work one does to make meaning from the death and life of the loved one (Klass,1996). While detachment was considered an individual task, Rosenblatt (2000) found that by sharing memories of their child, parents were able to construct an ongoing relationship with the deceased child and bring meaning to the loss. It may be that forging a continuing bond is family work. Further studies into the role of family plays in the formation of the continuing bond child are needed.

Grief Work

Following from the theories centering on detachment, the Grief Work Model predominated in the literature for many years. Grief work, was defined as a "cognitive process of confronting the loss, (of) going over the events before and at the time of death, of focusing on memories and (of) working toward detachment from the deceased (person)" (Stroebe & Schut, 1999, p. 199). Clinicians warned if grief work was not done, pathology would follow (Parkes & Weiss, 1983; Rando, 1984; Worden, 1982). A large part of this grief work was considered to be openly expressing one's inner emotions - mourning. Subsequent empirical work suggests that the Grief Work Model lacks validity (Bonanno & Kaltman, 1989; Wortman & Silver, 1989) and fails to take into account the cyclical nature of grieving, gender and cultural variations, and the social/interpersonal context of grief (Stroebe & Schut, 1999). Research is needed to further understand the importance of grief work, and as pertains to the study how/if families influence grief work.

Studying Family

Defining Family

Defining family for the purposes of a research study can be difficult. As Daly (1992) has suggested, "Families are groups that construct individual and shared meanings" (p.4). Family is the basic unit of any society (Badir, 1993), bridging the gap between the individual and the social and economic groups among whom the individual interacts. Family can be defined as both a cultural and economic construct. As a cultural construct, families have rules of formation, follow traditions, and engage in rituals and celebrations that are influenced by the various societies around the globe (Badir, 1993). The patterns of relationships among family members and the ways families spend time together are rooted in economic conditions of the larger society. While these larger societal issues are important in studies of grief and mourning, they will not be explored in this study.

Currently in North America, family forms are becoming increasingly diverse as increased numbers of women enter the workforce, as longevity increases, and as the birth rate falls (Becker & Charles, 2006). Family networks extend across household boundaries, often including members not related by birth or legal ties. These "families of choice" provide the supportive functioning that defines family both in practice and structure (Becker & Charles, 2006). However, when family is defined by this parameter, it is often difficult for the outsider to determine who is family. Bereaved parents will most often acknowledge that the deceased child retains family membership, but social circumstances may determine their acknowledgment of this membership (in) further adding to the complexity of defining family after the loss of a child.

Family as a Social Group

Families are groups, but they exhibit characteristics not seen in other social groups. "As a system moving through time, the family has basically different properties from all other systems. Unlike all other organizations, families incorporate new members only by birth, adoption, commitment, or marriage, and members can leave only by death, if then. No other system is subject to these constraints" (McGoldrick & Carter, 2003, p. 376). McGoldrick and Carter (2003) contend that even estranged family members have a role to play within families; this suggests that even divorce and death do not limit family membership. Within Yuen's definition of family (as presented in Chapter 1), even estranged family members may continue a commitment to the growth and development of certain family members. For example, bereaved parents who are divorced may not consider each other family. However, to their surviving children who are bereaved siblings both parents may well be considered family. Klass (1996) suggests the deceased child may also continue to retain family membership. He suggests that death simply transforms the relationship between the deceased person and the surviving family, but does not end it. Other characteristics as well reflect the unique nature of families as social groups including their levels of privacy, intimacy, and involvement.

These characteristics however may only be seen when the family is the unit of analysis, for the family maintains a level of privacy that is not readily available to non-family members (Daly, 1992). Families have privileged access to their life "backstage." This hidden side of family is where they interact with one another and create a whole that is greater than the parts. This whole can not often be seen when examining only individual members (Larzerlere & Klein, 1988; Gubrium & Holstein, 1990). Families also consist of subsystems (i.e. spousal, parent/child, siblings), and some information may be only available to certain family members or subsystems (Greenstein, 2006). It is this private level of interaction that the researcher most often seeks when studying family as the unit of analysis (Gubrium & Holstein, 1990). To understand families during bereavement following the loss of a child, research is needed that focuses on these interactions within the family.

A further characteristic of families is that members generally share some assumptions about the world they live in and these assumptions guide their transactions within their community and the larger society (Gubrium & Holstein, 1990). When first approached, families appear to display a collective consciousness, suggesting that they have organized themselves to deal with the world based on their commonly-held values and beliefs. It is only over time that the outsider becomes privy to the variations of individual members' interests, experiences, qualities, and beliefs (Daly, 1992).

When Nadeau (1998) explored family mourning, she found that making meaning of both the life and death of the deceased person involved interaction between family members, as well as transactions with the community based on societal beliefs and values. The sharing of family members influenced, and was influenced by, the experience of grief and mourning of other family members, as well as by the societal belief system in which they resided. To fully understand the complexity of family bereavement, it is important for the researcher to explore this phenomenon from both the individual and family perspective.

Family Bereavement Following the Death of the Child

The current body of empirical literature on bereavement following the death of a child demonstrates limited building on previous evidence of other researchers, resulting in a body of knowledge that has major gaps in our understanding and knowledge of this specific experience of grief and mourning. Exceptions are seen in the work of Davies, Klass, Rubin, Rosenblatt, and most recently, researchers from the University of Utrecht under the leadership of Stroebe, Stroebe, and Schut. While many studies have been conducted on the experience of parents, fewer studies have focused on siblings, and a paucity of studies exist on other family members such as grandparents. Many gaps in our knowledge of the experience of bereavement exist.

To inform the present study, this review first focuses on the studies of grief and mourning where family was the unit of analysis, then briefly examines the individual (i.e. parents, siblings, and grandparents) experience of family members during bereavement when a child has died, particularly as it informs our understanding of the interaction between individual and family experiences during bereavement.

When Family is the Unit of Analysis

> We live, die, grieve, and survive within a family context in which our enduring bonds to those who came before and those who come after us need to be recognized and included. We have grown accustomed in this culture to limiting our intimate acquaintances with death, to sheltering ourselves from the potential fragility of life. When our customary level of denial is punctured by death, we try as quickly as possible to make sense of the event so as to maintain our personal sense of control and stability (Shapiro, 1994, p. 5)

Shapiro (1994) theorizes that family process is disturbed by the death of a family member. These processes include families' normal patterns of interaction and communication, their definition of roles, and ongoing family narratives of shared meanings. However, in the empirical literature on the death of a child, few studies have explored the experience of families during mourning.

Although many titles in the bereavement literature on the death of a child use the term 'family,' the majority of these studies focus on individual family members. Only nine studies (Cimete & Kuguoglu, 2006; Denton & Green, 1980; Doran & Hansen, 2006; Gudmundsdottir & Chesla, 2006; Fletcher, 2002; Saiki, Martinson, & Inano, 1994; Martinson, Lee, & Kim, 2000; McClowry et al.,1987, White, 2002) were found that addressed bereavement of families. As would be expected and appropriate when little is known about a phenomenon, all nine studies used qualitative methods with open ended interviews. A methodological challenge was reported in two studies (Gudmundsdottir & Chesla, 2006; Fletcher, 2002) in which surviving siblings were excluded from investigation (with the exception of one adult sibling). Gudmundsdottir and Chesla (2006) were prevented access to surviving siblings due to the gate-keeping behaviour of families and recruiters who were leaders of support group programs. In four studies (Cimete & Kuguoglu, 2006; Doran & Hansen, 2006; Saiki et al., 1994; McClowry et al., 1987) interviews were conducted with both parents or with parent/sibling sub-groups. In one study, both parents and grandparents were interviewed, most often together (White, 2002). In the remaining two studies (Denton & Green, 1980; Martinson, Lee, & Kim, 2000) it was unclear what family members took part in the interviews but the authors reported that family interviews were conducted.

Defining family for the purpose of research is fraught with difficulty. To be included in this section of the literature review, the authors needed to address bereavement from the experience of family as opposed to viewing the individual experience or that of a particular dyadic group such as the parental subsystem. When the focus was on interactions between family members within particular dyads, the literature is reviewed in the following section entitled "Interactions of Family Members During Bereavement." While it can be argued that interactions between family members (i.e. marital dyad) constitutes "family" bereavement, for the purposes of this study with its focus on the larger family context, only the literature that examines the death of a child in the context of family functioning is included in this section.

Ongoing Relationship with Deceased Child

The one finding that was consistent across eight of the nine family-focused studies was that families maintained an ongoing relationship with their deceased child and used this ongoing relationship to adapt to the changed family structure (Cimete & Kuguoglu, 2006; Doran & Hansen, 2006; Gudmundsdottir & Chesla, 2006; Fletcher, 2002; Saiki et al., 1994; Martinson et al., 2000; McClowry et al., 1987; White, 2002). How the bereaved families adapted varied considerably. These variations will be discussed in the subsequent section. It is important to note, however, that the finding of an ongoing relationship contrasts with original theoretical work that emphasized the breaking of all ties with a deceased person as an important task of bereavement (Parkes, 1975; Worden, 1982; Rando, 1984). Of note in this regard is the research of Denton and Green (1980) who explored the issue of "the replacement child." Studying family functioning at a time when it was theorized that breaking the bond with the deceased was required in order for families to "regain their previous pattern of functioning" (p.5), Denton and Green suggested that the entrance of a new child into the family could re-establish a functional family balance only when the tasks of mourning (Worden, 1982) had been accomplished. Further, this study reported that when parents had "adequately dealt with these tasks. . .[they could] begin rebuilding their self images, fulfill futuristic plans, and relieve the societal pressure of the procreative function" (p.6). In contrast, White (2002) found that no families considered the birth of a subsequent child as a "replacement" but instead stressed that the deceased child would never be forgotten in their family. Further, White found that families reported that the birth of another child contributed to their healing. More recent theoretical work suggests that the task of bereavement is to continue a relationship with the deceased person, although the relationship differs from what it would be if the person were still alive (Klass, 1996;

Rosenblatt, 2000; Worden, 1991). Exploring family roles, boundaries, and identity in further studies may lead to an understanding on how families achieve this ongoing relationship and incorporate further children into their family.

Adaptation to Changed Family Structure

Within the family-focused studies, there was considerable variation in how family members adapted to their changed family structure. McClowry et al. (1987) studied 150 family members, including mothers, fathers/stepfathers and siblings within the first 7 to 9 years of bereavement after the child's death. Family members reported they had adjusted to their child's death by creating an "empty space." This empty space represented a way to continue to relate to the child who had died and therefore was no longer physically present in their lives. Family members reported that while a sense of emptiness continued, it changed over time, allowing them to integrate their pain and loss into their life and to find new satisfaction in living. The creation of the "empty space" was found to be relevant across cultures (Martinson et al., 2000) but that for some families, such as found in Korean cultures, this process may be done on a more personal level since grief in the loss of a child is often not externally expressed. Further qualitative research in this area could extend our understanding of how families create this "empty space" and whether it is an individual or family process.

The Use of Rituals during Family Bereavement

Family members reported the importance of family rituals in several studies. Although the form of family rituals varied with ethnic and cultural membership, their value in helping adjust to loss was common across several studies (Cimete & Kuguoglu, 2006; Doran & Hansen, 2006; Gudmundsdottir & Chesla, 2006; Martinson et al., 2000; Saiki et al., 1994; White,2002). The value of family rituals is best exemplified in the interpretive phenomenological study by Gudmundsdottir and Chesla (2006). In this study, family rituals used in response to families' loss offered a mechanism for maintaining a connection with the deceased child. Further, Martinson et al., 2000 reported that rituals acted as a stimulusof grief across cultures, allowing family members to openly express their grief.

The cultural variations of family rituals were reported in two studies. Doran and Hansen (2006) conducted an ethnographic collective case study with Mexican American families from the midwestern United States and found that traditional cultural rituals, such as attending services on the Day of the Dead, were particularly useful to family members as a means of remembering their deceased child and of allowing them to receive support from others. Japanese mothers also reported that attendance at public religious rituals such as the Buddhist services of remembrance (seven seven-day cycle services, and the one and two year anniversary services) provided bereaved family members with a place to mourn (Saiki-Craighhill, 2001a). As well, Chinese families reported that the Qing Ming Festival in early spring gives families the opportunity to attend the gravesite, cleaning and and repainting the name of the child on the gravestone (Martinson et al., 2000) This public place for mourning may be particularly important in cultures where grieving and mourning are generally seen as private and personal.

In some cultures, socially sanctioned public mourning rituals are seen as a way to limit the time for grief and mourning. In the United States, bereaved families reported that social support for their grief/mourning was short-lived and temporary, very often limited to the time from death leading up to funeral or memorial service, but ending once the services had taken place (Gudmundsdottir & Chesla, 2006). Similarly, a qualitative study conducted in Turkey with five bereaved families found that the cultural norm was for extended family and the community to give short-term support. Public displays of grief such as physical manifestations including crying uncontrollably, wailing, embracing the dead child, and hitting their heads against the wall were sanctioned only in the first few hours following the child's death (Cimete & Kuguoglu, 2006). Once the burial had taken place, there was limited acknowledgement of the dead child ever having existed.

Public mourning rituals and support from the social network and community have been found to co-exist with cultural norms of grief as private (Martinson et al., 2000). According to the Turkish study, visitors to the bereaved family's home are careful not to speak of the deceased child or the family's grief (Cimete & Kuguoglu, 2006). In one instance a bereaved father forbade any mention of the child by his own family. Saiki et al. (1994) found, as is expected within the Japanese culture, that grief was most frequently shared only between the bereaved parents often to the exclusion of other family members. When support came from outside the marital subsystem, it typically came from grandmothers.

In sharp contrast to the findings of grief as private or as something too painful to discuss, Doran and Hansen (2006) reported that Mexican American families received support from extended family, their church, and cultural community in the form of financial, emotional, social, and spiritual aid throughout their bereavement. In the three families interviewed for this investigation, the maternal grandparents of one family were included in interviews and they remarked that they felt it was their obligation to support their daughter and surviving grandsons. In this study, the death of the child was dealt with by the entire community and was done so openly.

In addition to public rituals, families also spoke of private rituals that aided their mourning. A private ritual that was commonly reported was the keeping of mementos, such as some of the child's clothing, favorite toys, or special blanket as a means to maintain the bond with the deceased child (Doran & Hansen, 2006; Gudmundsdottir & Chesla, 2006; Martinson et al., 2000; Saiki et al., 1994). In addition, Mexican Americans families maintained an "altar" where the child's photo, religious artifacts, and flowers were displayed. Families remarked that keeping cultural traditions such as the altar were particularly important in coming to terms with their loss (Doran & Hansen, 2006). Gudmundsdottir and Chesla (2006) reported a similar use of ritual wherein most families created a memorial to the child within the family home - sometimes in the kitchen or bedroom. These memorials served to keep the child's memory alive. In sharp contrast, all Turkish families reported that they had disposed of the child's possessions quickly and kept no photos of the deceased child in public view (Cimete & Kuguoglu, 2006). While the Turkish families reported that these practices were meant to help them forget their pain, the research report does not indicate whether family members found this to be true.

A common ritual of family members found in all four of these studies was the visiting of the child's grave, where family members often spoke to the deceased child as if he or she were present. Families stated that this practice facilitated their sense of connection with the spirit of their child. Rituals were consistently reported by participants to be significant to the family's adaptation to the loss and served as a means of connection between surviving family members (Cimete & Kuguoglu, 2006; Doran & Hansen, 2006; Gudmundsdottir & Chesla, 2006; Martinson et al., 2000; Saiki et al., 1994; White, 2002).

While rituals were found to connect surviving family members, changes in communication patterns (Fletcher, 2002) and relationships within the family (especially within the spousal subsystem) (Doran & Hansen, 2006; Martinson et al., 2000; Sakai et al., 1994) were found to either bring a distancing or closeness between family members. Several Japanese mothers reported that they found it difficult to accept their surviving children during bereavement (Sakai et al., 1994). These findings are consistent with those from studies where the individual is the unit of analysis and will be further discussed in the final section of this review. However, White (2002) found that rituals, including those that took place during family celebrations of holidays, contributed to the families construction of the continuing bond with their child. It may be that rituals are one resource the family uses to cope and adapt to the family stress resulting from the death of a child.

Adapting to the Loss

A common theme of these family-focused studies is adaptation or coping. Cimete and Kuguoglu (2006) described three stages of adaptation in their study of Turkish families including: first reactions - shock and disbelief in the loss, second reactions - sensitivity and inquiry into the past, and third reactions - adapting to the loss and returning to the former lifestyle. One participant remarked, "We still remember our child frequently but not as frequently as we had in the first months. Now we have been able to go back to our routines. Time is the cure" (Cimete & Kuguoglu, 2006, p.41). Of significance was the finding that all five mothers remained in the second stage of adaptation and exhibited depressive moods during the time of the study. In contrast to the mothers, all fathers and siblings moved on to the third stage of returning to their former lifestyle wherein they reestablished former routines. While other theorists have proposed stages of grief (Kubler-Ross, 1969; Parkes, 1975; Worden, 1982), it is important to remember that these families had been bereaved only 8 to 14 months. More recently theorists have proposed that grief, especially when a child dies, recycles for extended periods of time and perhaps a lifetime (Attig, 1996; Malkinson & Bar-tur, 2004-05; Wolfelt,1992). Perhaps the families in the Turkish study had not yet experienced this recycling and the mothers may have been working through the grief cycling more slowly. Or perhaps the work of grieving in this culture is assigned to mothers, allowing the rest of the family to "move on" or perhaps there is a greater acceptance that mothers grieve for the rest of their lives. Further studies investigating cultural differences and mothers' roles may provide an answer to these questions.

In addition to the use of rituals (as previously discussed), families cope with the death of a child using an array of mechanisms. Writing, physical activity (Sakai et al., 1994), cooking family meals, and watching videos of their family life before the death (Gudmundsdottir & Chesla, 2006) were used as ways to distract family members from their loss. Crying, especially in private, was common but served as a means to alleviate the pain and sadness of loss (Cimete & Kuguoglu, 2006; Martinson et al., 2000; Doran & Hansen, 2006). Cultural differences were seen in the use of reminiscing. While Mexican-American families frequently spoke of the deceased child (Doran & Hansen, 2006), Turkish families never did so (Cimete & Kuguoglu, 2006). In their cross-cultural study, Martinson et al. (2000) explored the changes in attitudes toward life and health that occurred following the death of a child. These changes included the increased desire to help others and to form meaningful relationships, a desire to create greater simplicity in the family's life, and more negative effects such as a loss of confidence in the individual's and family's continuing health and the medical system. White (2002) also found that intergenerational support contributed to family coping and adaptation. Most often this support load from the grandparents to parents and included being present for one another both physically and emotionally, acknowledging the child's loss (especially important when the child was stillborn), performing tasks including helping with funeral arrangements and assisting in decision-making, and providing information particularly about bereavement (one area of support in which parents lent support to grandparents).

These studies also raise questions about the effects of cultural traditions such as the limiting of information to adult subsystems (Sakai et al., 1994) and the avoidance of discussion of the grief experienced by survivors (Cimete & Kuguoglu, 2006). To what extent do these practices facilitate or prevent adaptation to the loss of a child? For instance, if children were fully informed and mothers were free to discuss their feelings with their children, would it be easier to care for the surviving children? Or if families openly discussed the child's death would mothers resume their former activities more readily? Or are there multiple strategies to address this that serve in one culture and not in another? Further research, perhaps guided by examination of family norms and values, is needed to answer these questions.

Responses to Loss

Somatic and emotional responses to grief are reported in the family-focused studies included insomnia, weight loss, loss of appetite, headache, and fatigue (Saiki et al., 1994), general body ache, (Martinson et al., 2000), depression, anger, and guilt (Cimete & Kuguoglu, 2006; Doran & Hansen, 2006; Fletcher, 2002; Martinson et al., 2000; Sakai et al., 1994). In the Japanese study, surviving siblings exhibited a range of physical problems, including asthma attacks and anorexia, and one child developed a nervous tic (Sakai, et al., 1994). These responses are commonly reported in the literature when individuals are studied.

Empirical Evidence to Support Theory

One study provided support for the theoretical work of Rando (1986). In Fletcher's (2002) case study of two families, five themes of family mourning emerged from the data, including: a) irrevocably changed lives, b) foreign experience (unnatural death), c) parental responsibility/duty (failure as parent), d) changing roles, and e) communication (often little took place). The first three of these themes had been suggested by Rando as reasons for the intense and lengthy grieving that is present during parental bereavement. However, the sample size (two families) of the study limits its findings.

These studies on the experiences of families following the death of a child provide us with a view of cultural variations found in grieving families. As well, they offer evidence of the importance of some rituals used in mourning but do not explore whether all family members share the experience of adaptation in their use. As an example, while Turkish families are reported to not speak openly of the deceased child, it is not clear if mothers benefit from this, as the researchers found that the mothers' adaptation was different from that of other family members. Research guided by concepts of previously established norms and values, as well as exploring possible changes in roles, routines, and interactions between family members is needed to inform our understanding of family experiences when a child dies. The current research study sought to explore family practices that aid/hinder family member grief in an effort to understand the role of family interactions. As well, this study explored a wider range of family functioning including an investigation of the norms, beliefs, and values that guide family practices during bereavement.

When the Individual is the Unit of Analysis

Research findings from studies where the individual is the unit of analysis need to be considered in this literature review for two reasons. First, with so little empirical evidence available through studies of families, evidence from studies of the individual experience informs our basic understanding of grief for families who have experienced the death of a child. Second, this study proposed to examine the experiences of the family unit during bereavement and how individual family members interacted with one another based on their individual experience of bereavement forming the interface between the individual and family. While the individual experiences of family members are more readily found in the literature than those based on family as the unit of analysis, much of our understanding of the grief experience of individuals when a child dies is based in clinical experience. As a whole, the literature on the grief of individual family members fits into different study categories and there is little evidence of building on previous findings. It is important to note that bereavement studies as a group suffer from a number of common problems, including high dropout rates, self-selection into studies, and little use of control/comparison groups (Birenbaum, Stewart, & Phillips, 1996). Hence, evidence of this phenomenon is still in the beginning phase of investigation in many areas, particularly in the areas of sibling and grandparent grief.

Most commonly, studies conducted on the individual's experience are divided into studies on parental grief, sibling grief, and the grief of grandparents. No studies were found that speak to the experience of aunts, uncles, cousins, or other family members. In this part of the literature review, the empirical literature will be examined to create an understanding of the common issues faced by those who grieve the loss of a child, including the unique features of grief when a child dies, the process and length of grief, the presence of physical responses and intense feelings of grief, and gender differences. However, while grief, in response to the death of a child. is powerful and intense for all family members, "it would be incorrect to assume that all members within the system respond in the same manner" (Ponzetti & Johnson, 1991 p.165). Hence the variations in experience seen within these three groups will be examined along with the themes of existing research in each of these areas. Reports from the clinical literature have been examined to aid in the identifying of gaps that exist in the present research knowledge.

Unique Features of Grief when a Child Dies

As reviewed in Chapter 1, the theory of Symbolic Interactionism suggests that the meaning individuals hold for an event affects their behavior with meaning based in the individual's belief system and values. Empirical evidence suggests that when a child dies, family members' belief systems, irrespective of culture, are disrupted (Braun & Berg, 1994; Lang & Gottlieb, 1993; Ponzetti & Johnson, 1991; Rando, 1986; Rosenblatt, 2000; Sakai et al. 1994; Talbot, 2002; Wheeler, 2001).

Forever and fundamentally changed. "The death of a child is the bereavement experience that most violates previous assumptions and meanings" (Miles & Crandall, 1983, p.53). Meaning reconstruction, a unique and critical aspect of the grieving experience, requires family members to confront existential questions including the meaninglessness of the loss and the sense of depersonalization that results (Lang & Gottlieb, 1993) in order for life to once again have meaning (Wheeler, 2001). This process has been found to have three phases including a) discontinuity, in which the meaning of the child's death could not be fit into the parent's previous held meaning structure (beliefs and assumptions about the world, i.e. Parkes assumptive world) seen in the parents asking "why?" b) disorientation, when the parent could no longer make sense of their world resulting in feelings of loss of personal control and purpose in living, and c) adjustment, in which parents achieved a reinterpretation of their meaning structures (Braun & Berg, 1994). Further, this study reported that adjustment was achieved in contact with people, activities, beliefs and values, connection with the deceased child, and personal growth. Parents may feel that following the death of their child they have an increased sense of purpose in life (Rogers, 2005). Often, family members relied on their religious faith to accept their child's death as just another part of life believing that their child's short life had a reason and purpose in the workings of their higher power (God) (Rosenblatt, 2000; Wheeler, 2001). As reported in family-focused studies, Rosenblatt (2000) found that parents, using rituals of remembrance, created an ongoing relationship with their deceased child. These rituals also contributed to the construction of meaning in the child's life. Nonetheless, parents reported a fundamentally changed worldview.

The nature of family relationships. While little empirical evidence is available that has directly investigated changes in the nature of family relationships during bereavement, some researchers have suggested that unique aspects of these relationships are important to understanding grief when a child dies (Robinson & Mahon, 1997; Sanders, 1979–80; Talbot, 2002). A brief review of these aspects is offered for the purpose of providing context for this study.

Sanders (1979–80) has suggested that the uniqueness of the parent–child relationship contributes to the intensity of parental grief. For parents who lost an only child, Talbot (2002) argues that it was the parent–child bond and loss of role as parent that resulted in the intense experience of parental grief found in her study. Long-term foster parents who experienced the death of their disabled foster child demonstrated the same intensity of grief as birth parents, leading the researcher to conclude that, "the child serves both as the parents' tie with the past, and also with their future in a sense of mortality; the death of a child serves to disrupt these links and to threaten our sense of our own mortality" (Schormans, 2004, p.363). Further, Gibson (2006) found that parents who experienced a sudden, dramatic death of a child reported no desire for recovery, expressing that this event was so debilitating that they could not imagine that their pain would end.

While the death of a sibling is a relatively rare phenomenon in North America, when it occurs it ends the relationship considered to be one of the longest and most intimate of a lifetime (Robinson & Mahon, 1997). Children who experienced the death of their sibling reported that they had gained maturity, coped well, and integrated the death into their life purpose and meaning (Balk, 1990; Lohan & Murphy, 2002; Martinson et al., 1987). Davies (1999) theorized, from her many studies of bereaved children, that perhaps the death of a sibling brings an altered view of life that does not readily fit with activities engaged in by their peers, making their interests different and leading to social withdrawal.

While the grief experience of grandparents has just started to be investigated empirically, clinicians (Reed, 2000; Galinsky, 2001) claim that grandparents grieve twice. One grief is experienced for the lost grandchild while the other occurs for the loss of their role as protector of their own child, the bereaved parent, possibly changing their interactions with their child. Empirical studies are needed to explore the extent to which relationships change as a result of bereavement especially in consideration of family roles, identity, and interactions including those that occur within the extended family network.

Responses Associated with Grief

Studies on grief responses (most commonly referred to as 'symptoms' in the literature) are numerous and focus on the emotional, physical, behavioural, and cognitive aspects of grief. Research instruments have been designed to assess the grief responses of both adults and adolescents, but questions exist about their accuracy in distinguishing grief from other phenomena such as depression (Neimeyer & Hogan, 2001). While most studies on grief when a child dies, such as those on sibling grief, grandparent grief, and parental support networks, are still at an exploratory stage, studies on parental grief responses have begun to move beyond descriptive to more predictive methods. Hence, more quantitative studies with larger samples and comparison groups are seen in this area of grief studies. However, since individual family members were not the focus of this study this section will only briefly identify the categories of grief responses for individual family members serving as background for understanding the family stories that are presented in chapter 5.

Physical responses. A number of physical responses have been reported in family members, with the most common being sleep disturbances (Davies, Deveau, de Veber, Howell, Martinson, & Papadatou, 1998; Lohan & Murphy, 2002; Pettle Michael, & Lansdown, 1986; Ponzetti, 1992) which have been found to be accompanied by nightmares in surviving siblings (Lohan & Murphy, 2002) and symptoms of dizziness in parents (Davies et al., 1998). Studies on the risk to parents' health are beginning to be seen in the literature through an extensive examination of Danish census data, in which Li et al. (2003) report that as a group, bereaved mothers' overall mortality rate was increased, especially related to death from unnatural causes and that bereaved mothers had a higher risk of being hospitalized for psychiatric disorders than bereaved fathers (Li et al., 2005). However, Birenbaum et al. (1996) provided contradictory evidence when investigating the health status of bereaved parents by means of the Duke-UNC health profile, a measure based on the World Health Organization's broad definition of health. In this prospective study, parents' scores on measures of physical, emotional, and social health did not drop significantly following their child's death. The results of this study suggest that the profile of responses measured may be an important consideration when assessing long-term risk to the physical health of family members. Further studies, using common outcome measures in different countries are needed in order to give us a complete picture of family health outcomes following the death of a child.

Cognitive responses. Studies of cognitive responses of bereaved family members generally explore three facets. The first, suicidal ideation has been investigated in all relationship groups (deFrain, Jakub, & Mendoza, 1992; Birenbaum, 2000; Talbot, 2002). In adolescents, it is often seen as a preoccupation with death in adolescents (Balk,1990; Birenbaum, 2000). When parents are not able to achieve other cognitive means to reconcile their grief, thoughts of suicide become common (Talbot, 2002). However, Rosenblatt (2000) found that thoughts of suicide, while common in bereaved parents, were most often fleeting allowing them to consider the possibility of reuniting with the deceased child. However, no studies have been conducted to investigate the completion of suicide.

The second cognitive response, lack of concentration and difficulty maintaining attention (Balk, 1990; Fanos & Nickerson, 1991; Pettle Michael & Lansdown, 1986) was found to result in a drop in school achievement. Further studies are needed to determine the risks to cognitive functioning for bereaved siblings.

Meaning making, the third component of cognitive response, was reviewed previously in this section under the in unique features of grief when a child dies.

Behavioral responses. A number of studies have focused on behavioral manifestations of grief during bereavement. Displays of stoicism (Wood & Milo, 2001), aggression or angry outbursts, and attention seeking (Powell, 1991) have been found. Activity is often thought to aid coping, particularly in instrumental grievers (Martin & Doka, 1996; Wood & Milo, 2001). Behavioral responses in relation to social activities have also been noted. Adolescents have been found to withdraw socially (Davies, 1999; Pettle Michael & Lansdown, 1986; Powell, 1991). Other studies have reported isolation (Sidmore, 1999-2000; Wood & Milo, 2000), seeking social support (Ponzetti, 1992; Schwab, 1990), difficulty dealing with the outside world (Saiki-Craighilll, 2001b) and decreased social competence in children (Birenbaum, Robinson, Phillips, Stewart, & McCown, 1989; Fanos & Nickerson, 1991). Increased use of drugs and alcohol is also noted, especially in reports of fathers' grief (Vance, Boyle, Najman, & Thearle, 1995; deFrain et al., 1992). Martinson et al. (1987) found that caregiving behaviors were common among bereaved adolescents with these behaviors related to self-concept scores. Teens scoring low on self-concept compensated through overachieving and taking care of their parents, while adolescents scoring high on self-concept also demonstrated caregiving behaviors but these were aimed toward peers or younger siblings. This group of responses is particularly important to the study of family experiences during bereavement since this research seeks to explore behavior of family members. Other than the Martinson et al. (1987) study, there was minimal analysis or interpretation of the meanings of the behavioral responses following the death of a child.

Emotional responses. A number of studies report on emotional responses to the death of a child among bereaved family members. Often, the findings of emotional responses come from studies in which the purpose of the research was on some other aspect of grief and minimal attention is paid to the significance of the emotional responses to healthy outcomes of grief and mourning. Nonetheless, these findings serve to demonstrate the wide range of emotions that commonly occur in response to the death of a child.

The most commonly reported emotional responses of grief include disbelief, guilt, anger, anxiety, depression, shock, numbness and sadness. These responses are seen in all categories of family members (Balk, 1990; Birenbaum, 2000; deFrain, et al,, 1992; Ponzetti & Johnson, 1991; Rando, 1980; Saiki-Craighill, 2001a; Wheeler, 2001), with one study reporting increased frequency and intensity of these responses in bereaved parents for up to nine years post loss (Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004). Studies of other relationship groups have uncovered additional emotional responses to the death of a child. Grandparents who have lost a grandchild as a result of sudden infant death syndrome (SIDS) have reported bitterness, regret, and resentment (deFrain et al., 1992). In a number of studies, bereaved siblings reported loneliness, fear, hopelessness, worry, inferiority, rejection and self-doubt (Balk, 1990; Birenbaum, 2000; Davies, 1991; Rosen, 1984-85). Rando (1980) found that when bereaved parents had experienced a number of previous losses, their coping ability was decreased, and their levels of anger and hostility were higher than those of bereaved parents for whom the death of a child was their first major loss. Finally, Saiki-Craighilll (2001a) found that Japanese mothers experienced waves of sadness, even when other emotions had stabilized.

Guilt is the most commonly reported and the most intense emotion for all categories of family members following the death of a child (Lang & Gottlieb, 1993; Rubin, Malkinson, & Witztum, 2000; Taub, 996; Wheeler, 2001), but its experience varies among parents, siblings and grandparents. Parents speak of guilt as a sense of failure in the fulfillment of their parental role; they saw themselves as not having protected the life that was entrusted to them. As a result, guilt has, at times, been found to be so severe that parents report that their strength and resiliency are overwhelmed by it (Rubin et al., 2000). When siblings speak of guilt, on the other hand, they do so from two perspectives. They report guilt resulting from what they feel they should have done to prevent the death of their sibling. More importantly, they report survivor guilt; they lived when their brother or sister died (Davies, 1999; Rosen, 1984-85). While survivor guilt has not been studied empirically for grandparents, clinical findings suggest that it is a predominant feature of grandparent grief (Galinsky, 2001). Since grandparents often view themselves at the end of life and close to their own death, they feel the "off time" event of a grandchild's death as a particularly difficult experience in which they feel guilty that they have survived when their grandchild has not. There has been no research that has included all three groups of relationships.

Depression as a grief response has also received considerable attention. Bereaved parents have been found to score higher on measures of depression than gender-matched non-bereaved parents at both two- and seven-years post-loss and lower than gender-matched psychiatric outpatients (Martinson, Davies, & McClowry, 1991). Much of the focus in the bereavement literature, however, has been on distinguishing between grief and depression. Broad-band depression scales, such as the Beck Depression Inventory or Symptom Checklist-90 revised (SCL-90R)(the one used in the above-mentioned study) have been used to measure grief (Neimeyer & Hogan, 2001), but researchers have questioned whether the use of these scales confound grief and depression.

Meij et al. (2005) conducted a longitudinal study of 219 bereaved couples and examined the differences between depression and grief. Using different instruments to measure grief (Inventory of Complicated Grief (ICG) and depression (depression subscale of the SCL-90R), the investigators found grief to co-vary with certain shared parent factors (child's age, cause and unexpectedness of death, and number of remaining children) and depression to co-vary with more individually focused factors (gender, religious affiliation, and professional help seeking). In addition, the researchers found that parents experiencing the highest levels of grief were found to be those whose child had died as a result of trauma (rather than illness) and that parents' grief scores were positively correlated with the age at which their child had died. Other important findings of this study pertinent to family experiences during bereavement were that parents were found to experience less grief and depression when there were other children in the family and that women scored higher on measures of both grief and depression than men. Further studies that explore how the family uses its combined resources to aid family members cope over time, especially those who may be experiencing a pile-up of these bereavement responses, are needed to increase understanding of the importance of family following the death of a child.

Time as Process for Family Member Grief

To understand family bereavement, it is important to recognize that grief and mourning are processes that occur over time. While the family-focused studies provide some evidence on adaptation and coping, further evidence is seen in studies of individual family members and will be reviewed here. However, a common problem of the literature is that many studies limit their focus to early phases of bereavement

(Birenbaum et al., 1989; Birenbaum et al, 1996; Davies, Gudmundsdottir, Worden, Orloff, Sumner, & Brenner, 2004; Gillis, Moore, & Martinson, 1991; Lang & Gottlieb, 1993).

Acute responses of grief lasting up to six years have been reported (Cole, 2000; Kreicbergs et al., 2004). Acute grief has been found to intensify for some parents throughout the first two years and only then slowly diminish (Cole, 2000; Kreicbergs et al., 2004; Rando, 1980) to the point where further significant adjustment does not take place (Hayslip, Allen, & McCoy-Roberts, 2001; Malkinson & Bar-tur, 2004-05; Martinson, Davies, & McClowry, 1991). Keesee (2001) found that scores on indices of grief decreased over time, especially when parents reported efforts to make sense of the child's death. But some parents report that they do not get over the intense pain and find great difficulty resuming life (Malkinson & Bar Tur, 2004-05; Martinson, McClowry, Davies, & Kuhlenkamp, 1994; Talbot, 2002). Grief becomes "interwoven in their lives and grows to be an integral part of their repertoire" (Malkinson & Bar-tur, 2004-05, p. 112). These findings suggest that longitudinal studies that explore grief responses over many years are needed.

As seen in the family-focused studies, adjustment (often described as accommodating, reconciling, reorganizing, healing, functioning and coping) for bereaved parents requires the use of many coping strategies. Schwab (1990) found these strategies to include: a) seeking the release of tension, b) avoiding painful thoughts and feelings (for some this meant keeping busy and avoiding reminders of the dead child), c) using a cognitive framework to understand and deal with the experience of loss, d) helping others, and e) relying on religious beliefs which give them hope and help them to maintain strength. When bereaved parents were able to address their spiritual needs, they experienced a greater capacity to cope with the death of their child (Meert, Thurston, & Briller, 2005; Klass, 1993). Through the use of multiple cognitive coping strategies, bereaved mothers have been able to re-establish their sense of control, experience less pain, and find growth in the experience of loss (Milo, 1997).

The process of grief and adjustment over time among grandparents has not been studied. As well, there is limited empirical literature on bereaved siblings. The grief of adolescents has been found to diminish over time improving after 18 months (Hogan, 1988), giving adolescents the opportunity to examine and learn from their loss (Hogan & DeSantis, 1994). An important finding of Hogan's (1988) study was that with time (approximately 3 years) the family began changing so that adolescents once more had a sense of being part of a 'complete' unit. Forward and Garlie (2003) suggest that the grieving adolescent may follow a 5 stage process, including a) "finding out," b) "avoiding reality," c) "facing reality," d) "turning the corner," and e) "finding new meaning".

A common problem of the literature on parental bereavement is that many studies limit their focus to early bereavement, leading to gaps in our understanding of the entire bereavement period (Birenbaum et al., 1989; Birenbaum et al, 1996; Davies, Gudmundsdottir, Worden, Orloff, Sumner, & Brenner, 2004; Gillis et al., 1991; Lang & Gottlieb, 1993). Further research is needed to examine grief and mourning over a longer portion of the bereavement period.

Role of Gender

To understand family bereavement it is essential to examine the differences in grieving styles. In the grief literature, "normal grief" has been defined primarily from a woman's point of view (Martin & Doka, 1996; Stroebe et al., 2001). Research on sibling bereavement has yet to distinguish between the grief experiences of brothers and sisters. As well, little evidence is available on gender differences in grandparents' experience with the exception of a brief comment in Ponzetti and Johnson's (1991) study that reported that grandmothers express the desire to talk of their deceased grandchild more often than grandfathers. However, gender differences are frequently reported in studies of parental grief where the focus is on mothers' and fathers' individual grief. To understand the experiences of family during bereavement and the behaviors seen, an understanding of differences of expression during grieving is needed.

Martin and Doka (2000; 1996) have suggested that it may be inappropriate to divide grievers along gender lines. They define persons who are emotive and help-seeking in their grieving as intuitive grievers (previously referred to as feminine grievers), while those who cope through a cognitive, problem-solving way in dealing with loss have been referred to by Martin and Doka (2000; 1996) as instrumental grieving (previously referred to as masculine greiving). While studies have not been done to estimate the division of grievers along gender lines, Martin and Doka (2000, 1996) suggest that it is highly likely that women are more likely to exhibit stronger characteristics as intuitive grievers while men are more likely to follow patterns of instrumental grief. However, these authors caution that it is unlikely that any given person is strictly an instrumental or intuitive griever and that in reality we all display some aspects of both ways of coping.

When studies are conducted on the basis of gender, mothers' grief generally appears to be more intense since their grief is often more public in expression and they are more likely to seek support and opportunities to share their experiences (Gillis et al., 1991; Klass, 1986-87; Lang & Gottlieb, 1993; Littlefield & Rushton, 1986; Schwab, 1996). Also, mothers have been found to ruminate more often than fathers and to be preoccupied with the loss, whereas fathers have been found to isolate themselves (De Vries, Dalla Lana, & Falck,1994; Sidmore, 1999–2000). Lang and Gottlieb (1993) found that the best predictor of mothers' grief scores was the suddenness of the death and that fathers' grief scores were best predicted by the intimacy of their marital relationship.

In contrast, fathers' grief has been found to be more private in nature, one where grievers work hard at managing and controlling their expression of emotion (Wood & Milo, 2001). Fathers will often postpone their grief work until the family, particularly the mother, appears to be coping well (Sidmore, 1999–2000; Schwab, 1992). Evidence indicates that when one spouse scores at an extreme end of the grief continuum, the other spouse is likely to score at the other extreme end (Dyregrov & Matthiesen, 1991) indicating that parents may take turns in their grieving. As well, studies have found that fathers express greater emotional stoicism and use activity as a coping strategy; they tend not to cry in public, and generally withdraw and think about things in private (Wood & Milo, 2001; McGrath, 2001).

Davies et al. (1998) found that mothers from five different cultures, when commenting on their spouse's grief, felt fathers' grief was different than their own but just as deep. Mothers thought fathers were more likely to blame themselves and had greater difficulty because they could not express their pain, coping instead by working extra hours or by expressing anger. Lang and Gottlieb (1993) found that while mothers rated their grief reactions as higher on the Bereavement Experience Questionnaire (BEQ), the authors questioned whether the intensity of grief for mothers is really different from that of fathers. When questioned directly in research studies about the intensity of their grief, fathers reject the idea that their grief is less than mothers, stating that it is just different. They further report that when their child dies they experience feelings of vulnerability, helplessness, and uncertainty about the future (Davies et al., 2004; Gilbert, 1989; Wood & Milo, 2001).

Martin and Doka (2000) suggest that measures of grief have an inherent bias; they tend to emphasize emotional expression and help-seeking behaviour. Further, Vance et al. (1995) found that perceived gender differences depended on what indications of grief were being measured, noting that when anxiety and depression were measured women showed greater disturbances; however, when excessive use of alcohol was used as a measure as well, differences between men and women levels of grief were virtually nonexistent. After an extensive review of the literature and based on their clinical findings, Martin and Doka (1996) suggest that it is better to describe grief by the way it is expressed and not by the gender of the griever. Gender has been found to be unimportant in predicting bereavement adjustment and although gender may cause the grief work to look different, both genders can successfully cope with loss (Hayslip et al., 2001).

Further research is needed to identify the dimensions of grief so that the experience for both intuitive and instrumental grievers will be clarified. When this has been accomplished, measurement tools that capture the full range of grieving will need to be developed and validated on diverse populations of grievers. Further, studies that explore the effects on identity of family members following the death and how this possible shift in individual identity affects family functioning are needed. While this study did not propose to examine gender issues directly, various expressions of grief were seen and the interplay of these expressions influenced the interactions of family members as will be further discussed in Chapter 6.

The Role of Social Support

The benefit of support networks has been researched by a number of authors producing the most consistent findings in any area of grief research. Social support has been found to be a key element in grief resolution (Davies et al., 1998: Hogan & DeSantis,1994; Hazzard, Weston, & Gutterres, 1992; Kissane & Bloch, 1994; Meert et al., 2005; Ponzetti & Johnson, 1991; Rando, 1986; Rosenblatt, 2000; Spinetta, Swarmer, & Sheposh, 1981;Talbot, 2002). Since this study did not examine the larger context of community and society, this review is limited to issues of social support within families.

Both parents and grandparents suggested that speaking with other members of the family.about the deceased child was helpful particularly when family members provided a sympathetic presence, reassurance, and assistance in meeting practical needs (Meert et al., 2005; Ponzetti, 1992; Rosenblatt, 2000; Talbot, 2002). Doran and Hanson (2006) reported that in Mexican-American families, grandparents and other family members felt that it was their obligation to support bereaved parents and siblings, both emotionally and financially.

Maintaining family connections is important since these connections have been found to be the primary support to grieving parents (Sundell, 1997), but family members must at times reach out to each other or create new sources of support so that they can progress in their grief work (Laakso & Paunonen-Ilmonen, 2002). As has been previously discussed, cultural norms may indicate which family members are available for support (Saiki, et al.,1994).

Studies on social support for children and adolescents generally focus on peer relationships. Hogan and DeSantis (1994), in their study of what helped and hindered adolescents in bereavement, found that when numerous people were present in the adolescent's support network, including extended family and peers, adolescents coped better with their grief. However, when the social network engaged in rumours and gossip, and people were insensitive to the feelings of the adolescent, the grief process was hindered. Of particular concern was when extended family members told adolescents to take care of their parents, thereby leading adolescents to focus more on their parents' grief than on their own (Hogan and DeSantis, 1994). The role of support within the bereaved family and the ability of grieving family members to support one another requires further investigation. Research is needed, in particular to examine the variations of support given and received as determined by defined relationships/roles.

Age of the Child at Death and Nature of the Relationship

Very few studies have examined age of the child at death as a distinct research variable, and only the parental bereavement literature reports on it. The few studies found suggest that the age of the child at death has little effect on the process parents experience as they grieve (Cole, 2000; Spinetta et al., 1981; Sundell, 1997), although contrary evidence provided by Kreicbergs et al. (2004), found that both mothers and fathers reported higher levels of distress when the child was nine years or older at time of death. However, when children died before or very shortly after birth some subtle differences are seen due to society's assignment of the lack of importance of the loss resulting in the parents' inability to talk openly about their loss (De Vries, Davis, Wortman, & Lehman, 1997).

When parental grief is examined, it is the parent–child relationship, not age, which is the crucial criterion for the type of grief experienced. For parents, the child's life begins in utero and is meant to continue beyond their life. Their 'child' is always defined in terms of the parent–child relationship whether the child is a minor or an adult. The child is not expected to predecease the parent and when this ‘off-time’ loss occurs it is thought to disturb the natural order of the world, resulting in a unique process of grieving (De Vries et al., 1994; De Vries et al., 1997; Malkinson & Bar-tur, 2004-2005).

Some deaths of children go unrecognized as loss by society. Miscarriages and stillbirths (DeVries et al., 1994) as well as the death of an adult child are often unrecognized as major losses for parents. When death occurs before birth it brings an end to the parents’ hopes and dreams for the new life. Other family members may not recognize the loss as significant and in need of support (DeVries et al., 1994). For parents of an adult child who has a spouse and children as ‘first mourners’, the intensity of parental grief often goes unsupported (DeVries et al., 1997). For the elderly parent who loses a child, a number of studies have found that grief becomes a constant companion until the parent’s death. At a time when roles have often reversed, parents are left without the physical and emotional support given by their child who has also become their caregiver (Moss, Lescher, & Moss, 1986-87; De Vries et al., 1994, 1997; Malkinson & Bar-tur, 2004-2005). These two instances of child death are outside the parameters of the current study.

Causes of Death

The cause of death has been found to influence the grief of parents (De Vries et al., 1994; Murphy, 1996; Rubin, 1981; Sanders,1986; Stillion, 1996) and will be reviewed to examine differences that may be seen during family bereavement, as well as to form the basis for exclusion criteria for this study. Sudden Infant Death Syndrome (SIDS) has been found to bring great difficulties in functioning for bereaved parents, especially mothers. These difficulties include heightened anxiety, a perception of the world as less safe, and lower resilience. As well, these bereaved mothers demonstrated ongoing changes in their relationships with their other children (Rubin, 1981). It is thought that the trauma associated with SIDS deaths is related to its suddenness, the lack of a known cause and the young age of the child at death (Martin, 1998). Grief is intense and long lasting as a result of the lack of emotional preparation that an illness often allows (De Vries et al., 1994). Sexual intimacy between parents can also be decreased or absent as a result (Irizarry & Willard, 1999; Feeley & Gottlieb, 1988-89, Rosenblatt,2000).

In deaths resulting from accidents, anger and frustration persist well into the second and third year of bereavement (Sanders, 1986). The intensity of emotion may lead to the inability of one parent to comfort the other and communication may shut down. Guilt can be heightened for grieving parents if the child and parent were in conflict at the time of the accident or when the death is thought of as preventable (De Vries et al., 1994). Stillion (1996) found that loneliness was a strong and enduring emotion for parents whose children died in accidents, as others shy away, not knowing what to say and fearing that this could happen to them. When the legal system is involved, grief can be further complicated as the process through the courts can be protracted, plodding, and can be perceived as unfeeling (Oliver & Fallet, 1995).

While families of children who have died as a result of suicide and homicide are not included in this study, a brief review is included in order to explain why they are excluded. Deaths resulting from suicide or homicide are found to present the greatest difficulties in bereavement (Cole, 2000; Murphy,1996) with exaggerated feelings of guilt, shame, and anger (De Vries et al., 1994).

Overwhelming rage is most often present and a longing for retribution is strongly felt when a child dies as a result of homicide (De Vries et al., 1994: Rando, 1993). Homicide produces a cognitive dissonance, disbelief, and conflict in a person's value system that is difficult to assimilate. Murphy (1996) found that intense feelings of rage, fear, shame, guilt, and vulnerability overwhelm the person's coping mechanisms, often leading the parent to withdraw from their support systems. Further, isolation intensifies grief reactions and too often closes off all communication as grief becomes severe, exaggerated, complicated, and prolonged (Redmond, 1996).

As discussed, deaths resulting from SIDS, suicide, and homicide present unique experiences during bereavement. Multiple studies, focusing on one of these causes of death at a time, are needed in order to fully understand the experience that follows death from each of these causes.

This section has reviewed the many factors that have been studied in the grief of parents, siblings, and grandparents as individual family members. But individuals do not live in isolation, they live in the context of family. To understand the grief of individuals, we must look to the family.

Interactions of Family Members during Bereavement

This section will report empirical findings regarding the interactions of family members during bereavement. While no studies have been conducted to investigate these interactions directly, some evidence regarding family interactions can be found in a number of qualitative studies on various aspects of individual grieving.

Interactions between Grandparents, Their Children and Grandchildren

While clinicians state that grandparents play a vital role in the function of the family, acting as a source of affective bonds and mutual support, little empirical work has been done to support this statement. The only evidence of grandparents' interactions with their children and grandchildren during bereavement is found in Ponzetti's (1992) qualitative study of 36 parents and 20 grandparents(these parents and grandparents belonged to the same family groups). He found that while parents often talked to grandparents about the death, grandparents were reluctant to speak of the loss with their own child (the deceased child's parent). As well, while both parents and grandparents reported a change in their feelings toward each other, only a few participants felt that their interaction patterns with one another had changed. A minority (34%) of the grandparents reported feeling differently about their living grandchildren, but these feelings were not identified or elaborated upon.

As previously discussed, grandparents are said to "grieve twice"—once for the deceased grandchild and a second time for their own child who is in pain and suffering the secondary loss of his/her role as parent. Ponzetti (1992) found that 38% of bereaved grandparents reported experiencing pain for their children (the bereaved parent), lending some evidence to the clinical findings that grandparents grieve twice. Further, this study found that the majority of grandparents reported feeling closer to their own children following the death of their grandchild. The role grandparents play in the grief and mourning in families when a child dies is understudied and requires further investigation.

Interactions between Siblings and Other Family Members

The little evidence available in the literature on the interaction between surviving siblings and other family members most often centres on the parent-child experience. Evidence regarding the loneliness of bereaved siblings suggests that it stems from the isolation surviving children feel from their parents. Parents have been reported to be so absorbed in their own grief that the provision of care and comfort to their surviving children has been found to be lacking (Davies, 1991). At these times, adolescents may be particularly at risk for acting out behaviours and increased aggression in an attempt to gain the attention of the parents (McCowan & Davies, 1995). Adolescents may also demonstrate increased sibling rivalry, hostile behaviours, and non-compliance with parents' wishes (Birenbaum, 2000).

However, contradictory evidence indicates that parents are able to observe the grief of their children and show concern for their distress (Lohan & Murphy, 2002). Parents have reported many signs of grief in their children, including affective responses, struggles to make meaning/existential concerns, social changes, avoidance of the topic of death, attempts to fill the void left by the deceased child, physical problems, school difficulties, and changes in communication and ways of relating with other family members. In particular, fathers observed that their younger sons, aged 10–14, were experiencing social, spiritual, and especially emotional difficulties. They believed their sons were distant and detached, perhaps as a result of feelings the boys were experiencing but lacking the resources to handle (Lohan & Murphy, 2002). However, no evidence is presented in this study to suggest how parents addressed these concerns in their children. In another study, adolescents reported finding parents to be supportive and guiding through their bereavement. Most often, mothers were found to be the primary support and the family member adolescents most often talked to about their grief (Hogan & DeSantis, 1994).

Rosen (1984-85) found that children often attempt to care for their parents. He reports that they often feel responsible to provide comfort to their parents and try to make up for the loss their parents have experienced. This behaviour can unknowingly be encouraged when other adult family members advise children to "take care of your parents." When this takes place, children may be prohibited from working through their grief and seeking the care they need while withdrawing and blaming themselves for their sibling's death (Davies, 1999). Adolescents have been found to demonstrate a clear compassion and empathy for their grieving parents often giving up their own needs to care for their parents. But parents often did not recognize this care since it could appear the adolescent was happy and not concerned or worried about their parents (Hogan,1988). Further, parents understood this appearance of happiness to indicate that the adolescent was no longer grieving the loss of his/her sibling. As will be seen in the research on the marital dyad, misunderstandings can occur when family members assume that behaviours of another, which are unlike their own, are indications of the absence of grief. It may be that when misunderstandings and lack of open communication occur adolescents are at further risk in their grieving.

Many aspects of the parent-child relationship are as yet unstudied. Riches and Dawson (2000) theorize that adolescents may be at risk as well when their developmental work is hindered by the overprotectiveness of parents as they try to keep their surviving children safe. In a study of parental grief following the death of an adult child, parents spoke of their overprotectiveness towards their surviving children and their attempts to hide or isolate their grief from them. However, it was reported that their suviving children and grandchildren were able to feel some of the void the parent felt and reported a sense of distancing as a result (Malkinson & Bar-tur, 2004-05).

The very young child, without the cognitive development needed to understand the permanence of death, may feel lonely in the loss of his/her playmate and need the companionship and support of remaining family members (Davies, 1999). Sekaer (1987) has theorized that when this companionship is unavailable young children will use creative solutions such as imaginary friends to act out their difficulties and arrive at mastery. Further research is needed to explore the nature of relationships among bereaved family members and to examine multiple perspectives of these relationships.

Interactions in the Marital Dyad

The marital relationship is reported to be an important resource for parents after the death of a child but bereavement also brings struggles to the relationship (Rosenblatt, 2000). In a review of the literature, Oliver (1999) reports that studies on the effects of grief on the marital dyad have focused on the couple's experience of withdrawal with decreased engagement and diminished communication, their experience of increased conflict and anger, and their decreased sexual relationship.

Spouses reported that their marriage was severely strained by the death of their child and while they generally wanted to withdraw from everyone, the withdrawal of their partner was particularly painful (Oliver & Fallet, 1995). High levels of marital disruption in the first year of bereavement when grief was intense were found, but as grief lessened, marital disruption decreased and couples reported greater satisfaction with their marriage, with couples rarely considering divorce (Bohannon, 1990–91). The longevity of the couple's relationship may have an effect on marital disruption. Longevity may make understanding of the other's grief easier as a couple's ways of coping have been found to become increasingly similar over the years (DeVries et al., 1997; Malkinson & Bar-tur, 2004–05).

Spouses, both as parents and grandparents of the deceased child (deFrain et al., 1992; Gilbert, 1989), expect each other to provide bereavement support and are surprised when this was not experienced. Most parents reported that they felt that they had lost their spouse, at least for a time (Gilbert, 1989). Arguments, conflict, and hostility are common during bereavement, particularly when differences in grieving styles are experienced, resulting in high levels of conflict when spouses misunderstand each other's patterns of grief (DeVries et al., 1997; Bohannon, 1990–91; Gilbert, 1989). Schwab (1992) found that couples experienced conflict in regards to their different coping styles. While women often felt angry with their husbands when they did not share their grief and they initially saw this as a sign of rejection and abandonment, anger subsided and the relationship improved as the couple's communication was reinstated. Men, on the other hand, experienced difficulty when the couple's sexual relationship was lost or reduced. They felt a lack of support and comfort as a result of the denial of the sexual relationship. This study found that short tempers and general irritability was experienced by both partners resulting in more arguments. Spouses' perceived discordance in their coping strategies were found to be more strongly correlated with their psychological symptoms than was their absolute measure of discordance (Dijkstra, van den Bout, Schut, Stroebe, & Stroebe, 1999). When spouses felt supported by their partner, they experienced greater feelings of marital satisfaction. For conflict to remain at a minimum, it was important for spouses to acknowledge differences in grieving, including an acknowledgement that expressed grief does not equal the intensity of their partner's feelings of grief nor his/her love for the deceased child (Irizarry & Willard, 1999).

While marital conflict has been reported to stem from a lack of partner communication or miscommunication, differences in grief style, and differing beliefs in the appropriate amount of public display of their grief (Gilbert, 1989), some couples reported greater closeness with their partner (Bohannon, 1990-91, Rosenblatt, 2000). When couples were able to engage in open and honest communication, especially about their child and their grief, express their emotions, and maintain a physical closeness through hugging and touching (Rando, 1986), their ability to remain positive about their relationship increased. Increased communication resulted in decreased conflict, the return of satisfaction within the marriage, and a decrease in the perceived importance of their different styles of grief (Feeley & Gottlieb, 1988–89).

However, conflicting evidence is reported. Wood and Milo (2000) found in their qualitative study that when fathers used stoicism and sought distance from their family members, marriages remained strong. The authors do not report the length of bereavement in this study; it may be that as the couple re-establishes their relationship as bereavement continues, their communication and support of each other returns and the marriage remained strong. Further studies, particularly longitudinal studies, are needed to increase our knowledge on the short and long-term effects of communication on the marital relationship during parental bereavement.

Further, the erosion of sexual intimacy has been reported to occur when couples lose interest in sex due to exhaustion from grieving, fear that the closeness will increase their feelings of pain, and fear of pregnancy particularly when sex is seen as a reproductive function that can produce a replacement child (Bohannon, 1990–91; Hagemeister & Rosenblatt, 1997). Lang and Gottlieb (1993) found that a) younger mothers were angrier and experienced more yearning when levels of sexual intimacy were high, b) fathers experienced more guilt, a sense of meaninglessness, fear, and isolation when low levels of emotional and recreational intimacy were experienced, c) fathers experienced higher levels of stigma when lower levels of sexual intimacy were reported, and d) when couples had considered separating, fathers experienced greater anger, yearning, and stigma. In this study, the researchers used the Personal Assessment of Intimacy in Relationships (PAIR) instrument, along with the Bereavement Experience Questionnaire (BEQ) to measure couple relationship. The PAIR measures sexual, emotional, recreational, and social intimacy and when paired with the BEQ allows a thorough inspection of all aspects of the couple's relationship during bereavement. While it appears that the use of PAIR added further information on the experience of grief and the couple relationship, it is the only study on the marital relationship that incorporates this measure, and hence the study findings have not been confirmed or supported by other studies. Further use of these instruments may provide a better picture of the effects of grief on the marital dyad.

The pre-death relationship has also been found to influence grief resolution. When couples are in a supportive relationship, this support continues and a quicker resolution of grief is seen (Klass, 1986–87). However, for couples already experiencing marital difficulty, bereavement may bring about the end of the marriage. Klass (1986-87) suggested that perhaps couples decide that solving the problems in their marriage just doesn't seem worth the effort now that they are aware that they can survive a major loss, leading him to remark: "Marriages don't die with the death of a child, but often they receive an overdue burial" (p.247). However, much of the information on marital disruption is anecdotal, with reports in the literature of divorce rates ranging from 1.5% to 85% with similar variation in the rates of marital dissatisfaction (Oliver, 1999). Clearly this range of variation holds no meaning for our understanding on the connection between the death of a child and divorce rates. Further study is needed to inform our understanding of marital relationship following the death of a child.

In reviewing the literature on the effects of a child's death on the marital relationship, Oliver (1999) reported that this literature is scarce in general and lacks methodological rigor. He further found that refusal and dropout rates for these studies are as great as 50% with many parents stating they did not want to talk about their experience. As well, recruitment of participants was found to be most often from support groups or treatment programs with little use of control/comparison groups, leading him to question the significance of these refusals and wondering if more marital disruption is present for bereaved parents than is reported in the literature.

Further research is needed to explore the relationship between parental bereavement adjustment, marital discord, and the length of the partner relationship. As this review suggests, some factors that contribute to the experience of conflict and its resolution within the marital relationship have been examined, but further research is needed to understand the effect this has on family interactions. Longitudinal studies would contribute to our understanding of how this important family relationship changes over the course of bereavement. In the next section I will discuss how my study was designed to build on what is reported in the literature and to address the gaps I have identified in this review.

Using the Family Theoretical Literature to Guide Research

Family theorists have proposed that it is only by thoroughly understanding the unique dimensions of loss that grieving families can be assisted with interventions that most effectively address their issues during bereavement. In the North American culture with its emphasis on independence, studying bereavement with its assumptions of social connections, attachments, and human interdependence, can be a difficult process (Shapiro, 1994). Further, grief and mourning expose our vulnerability to fate. As seen in the empirical studies many emotional and practical implications result from the death of a child and the family must absorb these changes while continuing its everyday work as a family unit. Shapiro (1994; 2001) has theorized that family processes are disturbed by the death of a family member. These processes include families' normal patterns of interaction and communication, its definitions of roles, and its ongoing family narrative of shared meanings. In addition, grief disrupts the very stability of the family as it works to manage the intense emotions all members are experiencing. As evidenced in both the family and individual empirical studies, gaps that relate to the sensitizing concepts introduced for this study are present in our understanding of the family experience of bereavement following the death of a child. In particular, the family theoretical literature informs our thinking on the importance of family norms, family routines, roles within families, and family interaction including patterns of communication. Theorists (Carter & McGoldrick, 1989; Nadeau, 2001; Shapiro,1994; Walsh & McGoldrick, 1991) have suggested that bereavement must be viewed as both a private and subjective experience of the individual as well as one that is systemic in its interweaving of reactions in the family, community, and culture wherein family members influence one another. This influence was most clearly discussed by Gilbert (1996) in which she theorized that family members engage in "differential grieving" whereby individuals could have the same objective loss but that their individual experience would differ due to their unique subjective relationship with the deceased.

Murray (2005) identified a common difficulty for family scholars when she examined the bereavement literature and concluded that, in general, these scholars focus on the individual process of bereavement despite the fact that "death does not occur in isolation" (p. 81). Murray proposed that following death family members interact with one another in ways that affect the functioning of each other and, therefore, models are needed that address the loss as a system. One such model, developed by Moos (1995), provided researchers and clinicians with the way to view the interdependence within the family process and examine how family members influence each other's coping and reactions during bereavement. The model further suggests that the family's history and culture will impact family functioning and must be considered when studying bereaved families. This model still requires further empirical testing.

Other useful theories proposed in the adult bereavement family literature are seen. Boss and Greenberg (1984) suggests that with some losses boundary ambiguity exists in which families experience confusion as to who is in and who is outside of the family system. This ambiguity is particularly relevant when a person is thought to have died but no body has been found as happens in war (missing in action) or in kidnappings. However, boundary ambiguity may also be a useful concept to explore for families who have experienced the death of a child and are striving to create an ongoing bond with the child through rituals and family storytelling. Further, Nadeau (1998) explored the family construction of meaning in the life and death of an adult family member. She found that family members influenced one another in this process of meaning making through sharing their beliefs about the world as well as in relating their experiences with the deceased. It may well be that this process of meaning making is also relevant to families who are bereaved of a child.

One of the underlying questions in the bereavement literature focuses on the desired/healthy/functional outcome of bereavement. Recently, Balk (2004) theorized that bereaved persons recover from their loss. In the January, 2008 addition of *Death Studies,* leading bereavement theorists refute Balk's contention of recovery from bereavement and suggest that more appropriately "more neutral terms such as change or resolution" are needed in order to speak to the "transformative outcomes" (Tedeschi & Calhoun, 2008, p.27) that have been theorized in the literature as post-traumatic growth (Tedeschi & Calhoun, 1996) and as resiliency frameworks (Sandler, Wolchik, & Ayers, 2008). The model of "contextual resilience" (Sandler et al.) may be particularly important for families during bereavement in that the theory emphasizes the person-environment transactions in the development of resilience (an important family theory concept) and the risk and protective factors that are present for individuals on the family level.

Together with the empirical literature, the family theoretical literature has the potential to inform our thinking of the importance of family in the process of bereavement following the death of child. This thinking leads to conducting studies that allows us to examine "an unfamiliar reality, with new rules, a new language, new relationships, [and] questions" (Kagan, 2001, p. 5). Studying family responses to the death of a child is an important step in the process of understanding the bereavement experience.

Summary

Research on family bereavement when the family is the unit of analysis reveals that families desire a connection with the deceased child and use rituals to achieve this connection. Further, evidence suggests that culture plays a large part in mourning and guides the experiences of grieving families. Studies on individual grieving support the findings found in these family-focused studies. In particular, studies of parental grief give evidence for an adaptation during bereavement that is achieved through rituals and routines, such as viewing photos of the child and maintaining spaces for remembrance. However, family-focused studies have not yet explored whether individual family members interacting with one another create a family experience that is separate from the individual experience during bereavement. Through the use of sensitizing concepts introduced in chapter 2, together with theoretical understandings from the family literature, research to explore the ways in which families interact, adapt their roles and routines, as well as form a new identity incorporating the deceased child through establishing a continuing bond would expand our present knowledge on the experience of families following the death of a child.

Relevant to this study, little is known on how individual responses influence the response in other family members. While the individual experience of parents, siblings, and grandparents have been investigated to varying degrees, it is not known how these various relationships interact with one another and the contributions each brings to the experience of family bereavement. As well, studies have not effectively identified individuals at risk for difficulty in adjustment or, for purposes of this study, how families may assist the individual in decreasing their level of risk. The sensitizing concepts of interaction, coping (both family and individual), and adaptation may assist in guiding this needed research.

To date, very few studies have investigated the long-term effects of the death of a child on family functioning and no studies have examined how family routines evolve during bereavement. Interactions between family members have not been directly studied. In this study, I will examine family routines and roles including the interactions among family members and variation in these interactions based on the family member's role and relationship within the family.

While not included in this review, the clinical literature, especially in the area of family therapy, suggests that grief is an intergenerational, shared developmental process where family communication is essential for families to continue its work as a family unit. This study further proposed to examine these intergenerational interactions including family communication. Identification of these gaps in the literature on the phenomenon of family bereavement led to the research questions that formed the basis for this study.

The Research Questions

Main Question:

What is family bereavement in the context of families who have lost a child?

Sub Questions:

1. What are the family's norms, values, expectations, and patterns of behaviors during bereavement following the death of a child?

2. What are the integrated family stories that represent each family's experience?

3. How does the family describe and understand grief, mourning, and bereavement?

4. What do individuals perceive as patterns of family behavior that aid/hinder their experience?

5. Do individuals differentiate between family patterns and experiences and individual patterns and experiences during bereavement?

6. How do individual experiences and expectations influence the family's experience during bereavement?

CHAPTER 4
METHODOLOGY

In this chapter, I describe my research methods in the ethnographic approach, the qualitative research method I used in this study. My research question on the family experience during bereavement centered on family system phenomena, family dynamics, and the meanings, understandings, and perceptions of multiple family members (Rosenblatt & Fisher, 1993) so a qualitative method was "advantageous in studying topics where feelings, thoughts, and accounts are complex, qualified, ambivalent, situational, or different at different times" (Rosenblatt & Fisher, 1993, p.173).

Research Design

Focused Ethnography

Ethnography is about building the pieces of culture via accounts of a phenomenon through the steps of building the relations (methodology) in order to arrive at an understanding (accounting of things) of a phenomenon (.Agar, 1980). This includes a consideration of what pieces and relations are critical and must be present and those that are merely optional. Ethnography allows the researcher to fit together the pieces of specific accounts of a culture into a picture of the "whole" of a culture. In searching for patterns in the accounts of participants and seeking an understanding of their perception of "the flow of events in their lives" (Agar, 1980, p. 194), the ethnographer creates an interpretation of these accounts.

In contrast to conventional ethnography, which requires the researcher to participate in people's daily lives "in the field" over an extended period of time (Hammersley & Atkinson, 1995,p. 1), focused ethnography is commonly used to elicit information on a specific topic or shared experience, allowing for individual differences in points of view (Knoblauch, 2005). Where conventional ethnography explores the culture of a group within their natural setting, examining all aspects of their beliefs, values, and behaviors, focused ethnography is a useful method to employ when a specific phenomenon of the group has been identified before the study begins (Muecke,1994). Conventional ethnography is employed when it is expected that all members of the cultural group are familiar with each other. However, in a focused ethnography participants may not know each other but simply share an experience that is the phenomenon under study (Morse & Richards, 2002).

Short-term field visits or interviews (Morse & Richards, 2002) and audiovisual technologies are used to collect a large amount of data in a relatively short time frame (Knoblauch, 2005). This specificity results in an intensive and rich data set, just as in conventional ethnography, but only on the distinct phenomenon being studied (Morse & Richards, 2002). Further, the method of focused ethnography lent itself to an investigation into the sensitive subject of bereavement where the extensive participant observation required by conventional ethnography might have been intrusive and overwhelming to those being studied.

Ethnography is a process which requires openness to the unfolding action, where features cannot be known in advance, and knowledge emerges as the phenomenon is examined. The methods 'grand tour' questions and general probes (Spradley, 1979) allowed me to change directions recognizing that it was not always important to be asking the *right* question, for sometimes the best information came by asking the *wrong* question while I remained open to the data being offered by participants (Spradley, 1979). Focused ethnography gave a "disciplined unraveling of the breadth and complexity of relation.... It furnishes knowledge that is well worth having" (Rock, 2001, p. 31). It is within this epistemological frame that this study of family bereavement occurred.

In this focused ethnography participants were all family members who had experienced the death of a child but had varying relationships to the child. Most often, they participated in interviews as a family group and as an individual family member. A few exceptions occurred when a family member was unable to present for the family interview or on one occasion when a father refused to take part in an individual interview (see table 1). This strategy allowed the collective and individual perspectives to be represented. Each of the 13 families in this study were asked to choose a pseudonym for their family and for their child who had died. I then used the role relationship within the family to establish participant codes (i.e. Brother Smyth, Mother Jones, Aunt Choice Baker).

Challenges When Family is the Unit of Analysis

Families present logistical and ethical challenges when studied as the unit of analysis, leading many researchers to interview one family member at a time. In my study the most frequent logistical problems researchers face: gatekeeping by the family spokespersons (most often women), difficulty in accessing men, gaining the perspectives of instrumental grievers (Daly, 1992), and difficulty arranging an interview time with multiple family members (Allan, 1980) did **not** occur. By interviewing families, difficult-to-recruit individuals had the opportunity to be included in the study. I found that as Daly (1992) has suggested, in the family interviews men took an active part in the interview. Further, I was able to develop a fuller picture of the family experience during bereavement following the death of the child by including the perspective of multiple family members who had a variety of relationships to the child. As well, I had the opportunity to explore interactions of these family members.

Family interviews may also raise ethical concerns in that family members are individuals and must consent and remain involved in the study for data to be collected and analyzed as family data (Rasher, Kaufert, & Havens, 2000). Gatekeeping often excludes the participation of children because parents believe that their children are too vulnerable to take part in such studies. In my study parents encouraged their children to participate and, at times, I felt some concern about their ability to give their freely formed assent. When these questions arose, I took special precautions to ensure that children knew they had the right to refuse to participate. The researcher studying families is also challenged in protecting the individual's right to privacy as it is possible for one family member to share information that other family members would prefer to keep private. This concern was demonstrated when family members in their individual interview would remark one something and add that they had not felt they could tell their "truth" in the family interview for fear of hurting other family members feelings. On two occasions when this private information presented was crucial to the family story, I sought permission from the individual before the information was included in the family story. On both occasions this permission was given and provided much richer look at family interactions for the family story. Spradley (1979) reminds us that participants and researchers do not necessarily hold the same values and beliefs, and therefore, I strove to remain ethical and respectful of participants throughout the research process.

Benefits of a Qualitative Research Approach When Family is Studied

Generally, qualitative family research answers questions that examine family system phenomena and family dynamics, including the congruence and incongruence of multiple family members' viewpoints, as well as theoretical questions of the meanings, understandings, and perceptions of family members. It assumes that family is the focus of analysis. By collecting data from various family members, I was better able to understand the richness and complexity of family life following the death of a child.

Critical data was contained in the meaning family members made from their behaviors, feelings, and thinking about and within their family and the details and idiosyncrasies of what people communicate about their family (Rosenblatt & Fischer, 1993). By using the qualitative method of focused ethnography, I was able to question and explore the behaviors and communication patterns I was observing in the family interview. Further, since "qualitative strategies are also advantageous in studying topics where feelings, thoughts, and accounts are complex, qualified, ambivalent, situational, or different at different times" (Rosenblatt & Fischer, 1993, p.173), through this method I was able to fully explore the nuances of the emotional topic that has not often been studied from a family perspective (Rosenblatt & Fischer, 1993).

Setting

A central tenet of ethnography is "that people's behavior can be understood only in context; that is, in the process of analysis and abstraction, the ethnographer cannot separate elements of human behaviour from their relevant context of meaning and purpose" (Boyle, 1994, p.162). In order to examine participants' behaviours and their underlying beliefs and attitudes during bereavement in the death of a child, the setting for this study was family. However, as I discussed in the literature review, grief and mourning are complex issues with crucial elements present on both the individual and family level. Hence, to study the phenomenon of family bereavement and to answer the research questions of this study, the units of analysis were families as groups and individual family members. As expected, the type of information found when the individual was interviewed was somewhat different from the information obtained when the family group was interviewed (Julien, Bouchard, & Gagnon,1992; Larzerlere & Klein, 1988). This occurred for two reasons: a) the questions asked in the family interview focused on family-related experiences and behaviours, such as norms and routines, whereas in the individual interviews questions sought an understanding of the family member's internal experience and behaviours, and b) individual interviews sought the personal perceptions of family relationships.

When families were the unit of analysis, interactions between family members were observed and added a dimension and understanding that was distinct from and greater than the parts under study when only individuals were examined (Larzerlere & Klein, 1988; Gubrium & Holstein, 1990). Some beliefs and assumptions about the world they live in were shared by family members and it was observed that these beliefs and assumptions influenced the ways in which families organized themselves to deal with the world (Gubrium & Holstein, 1990). When interviewing families as a unit, I was able to observe interactions between family members that revealed some of the "backstage" behaviour as described by Goffman (1959) that was central to understanding the influences family members had on one another. Examples of this were seen in the Smyth family, during the family interview. Uncle Choice explained Father's fund raising activities were an important part of his mourning while he sat silently and softly crying. On the rare occasions when he did interject a comment, multiple family members validated his comments in words such as Brother's statement of agreement "Great!" As well, this family appeared to have many inside jokes that would be shared among members through simple words, not always understood by me, but noted through field notes in the transcripts such as: "(Lots of laughing and exchange of knowing glances, shaking heads in agreement)."

When the individual was the unit of analysis, information on the personal experience of grief, the emotions, cognitions, and the individual's behavioral (mourning) strategies, as well as the individual's perception of the family experience as it unfolded within their family, was revealed. A fuller understanding of family bereavement was obtained by comparing, contrasting, and synthesizing the data from these two units of analysis.

The setting of family bereavement varied greatly in terms of family structure and the events leading up to the death of the child. Family structure and individual perceptions of relationship strength could be seen in the genograms. In general, these genograms reveal the intergenerational support of bereaved families, as well as variations in structure and relationship quality. A further aspect of the setting for family bereavement was the cause of the child's death. Three families experienced the sudden death of a child as the result of accidents. Two families experienced the sudden death of a child from an undetected medical condition (SIDS, AV malformation). Four children had died as a result of cancer following nine weeks to one year of treatment, and four families experienced the death of their child from a chronic illness. Within these four families, two children experienced congenital conditions that resulted in severe disability. For the remaining two families, the child was well most of their life with intermittent exacerbations of chronic disease which required frequent hospitalizations and outpatient treatment.

Study Participants

I interviewed 13 families and 35 individual family members (see Table 1). Each family group selected pseudonyms for their family and their child. Family groups consisted of one to eight family members. I interviewed 35 individuals including 12 mothers, 8 fathers, 7 siblings (M = 4, ages 15, 17, 18, 20 yrs; F = 3 ages 12, 15, 27 yrs), 3 grandmothers, 4 aunts (2 choice) and 1 uncle (choice). All participants were Caucasian of European ancestry. They ranged in age from Mothers 26-57 years at the time of interview (25-44 at time of child's death), Fathers 34-60 yrs (30-44). Ages of Grandmothers, aunts and uncle were not recorded. All mothers and fathers, as well as most other participants had some post-secondary education (exception one grandmother and one aunt had graduated from high school).

Families were asked to decide for themselves who was to be included in the family interview for the purpose of exploring their bereavement. I asked the spokesperson to invite all family members who they thought would have important information to share on the phenomenon. The definition of family chosen for this study is sufficiently broad so that participants defined various relationships for inclusion as their family members. In some circumstances, family members who were asked to participate, declined. On these occasions the family spokesperson stated that the family member thought the interview would be too painful. On a number of occasions family members that I would have liked to have interviewed were not accessible through the family spokeperson(s) or in the geographical area. These potential participants included the Damant paternal grandmother who was present at the scene of the child's death but with whom the family spokesperson is on tenuous terms. Mother Stewart who no longer spoke to Father, and Fraser and Barnes surviving siblings who were away from home for the summer and who also did not speak of their sister's death, according to these mothers.

Two children died suddenly from a previously undetected medical condition (SIDS, AV malformation), and 4 children were ill over a prolonged period of time. Three children were developmentally delayed with 2 of these also experiencing multiple physical handicapping conditions. The children had died 8 months to 30 years (<1 yr n = 4; 1-3yrs n = 3; 3-5 yrs n = 1; 5-10 yrs n = 1; 10+ yrs n = 4) prior to the commencement of the study.

Table 2

Participants

Family Pseudonym	Pseudonym of Child	Attended Family Interview	Attended Individual Interview
Smyth	Harry died in 2001 at the age of 15 years from cancer	Mother, Father, Brother, Grandmother, Aunt (maternal), Aunt Choice, Uncle Choice	Mother, Father, Brother, Grandmother, Aunt (maternal), Aunt (paternal), Aunt Choice, Uncle Choice
Jae	Sarah died in 2005 at the age of 7 years from a seizure disorder	Mother, Father, Brother 1, Brother 2	Mother, Brother 1, Brother 2
Jones	Patrick died in 2006 (Jan) at the age of 7 years from a mitochondrial disorder	Mother, Father	Mother, Father
Baker	Helen died in 1980 at age of 5 years from cancer	Mother, Father	Mother, Father, Aunt Choice
deJong	Hannah died in 2005 at age of 5 years from playground injury	Mother, Father	Mother, Father
Barnes	Clare died in 2006 (Jun) at age 11 years from cancer	Mother	Mother

Table 2

Participants (continued)

Family Pseudonym	Pseudonym of Child	Attended Family Interview	Attended Individual Interview
Myhre	Ray died in 2006 (Oct) at age 14 years from cancer	Mother, Sister	Mother, Sister, Grandmother (by phone)
Fraser	Neil died in 2002 at age 12 years from septic shock, IDP	Mother	Mother
Damant	Ben died in 2006 (Sep) at age 12 years in a car accident	Mother, Father, Brother 1	Mother, Father, Brother 1
Anderson	Ty died in 2006 (Jul) at age 7 years from a heart condition	Mother, Grandmother	Mother, Grandmother
Schmidt	Mateo died in 1997 at age 8 years in a car accident	Mother, Father, Sister 1, Sister 2	Mother, Father, Sister 1, Sister 2
Broders	Katrina died in 1993 at age 6 years from AV malformation	Mother	Mother
Stewart	Baby Lawrence died in 1997 at age of 3 months from SIDS	Father	Father

In the family interviews 1-7 family members were present representing various constellations of family memberships. Two of the couples who were interviewed together (Jones and deJong) chose to exclude family members living outside the house because they believed the experience of family bereavement was primarily an experience of their household. The Jones family had no surviving children and the deJong sibling (five years old) was too young to take part in the study. The Baker family was interviewed as a couple but their family story also included the perceptions of Aunt Choice who was included by way of an individual interview. The Baker family chose not to include their surviving son who was 3 ½ years old at the time of his sister's death, nor a daughter who was adopted two years following the death. Mother Baker spoke with her surviving son (now age 30) and reported that he indicated that he had very few memories of his sister's death and felt he could not contribute in a meaningful way to the family interview. In four families (Baker, Barnes, Fraser, and Stewart) the parents were divorced. Both mothers Barnes and Fraser stated that their former husband and surviving son did not speak of their loss; Mother Fraser had informed her former husband of the study but he chose not to participate. Father Stewart's interview was conducted following a casual meeting in which he stated that he had experienced the death of his son 30 years ago and that he subsequently became divorced even though he considered his marriage a good one previous to this death (a negative case). He no longer spoke with his ex-wife and his surviving two children did not speak of Baby Lawrence, hence he felt it would be ill-advised to include them in the family interview.

The interview with Mother Broders only was conducted to capture the phenomenon from the perspective of a long-term bereaved family as well as a verification interview. Mother Broders was a facilitator of a local bereaved parents' self-help group and provided information on her own family's experience, as well as her perceptions on the applicability of the study findings to bereaved parents whom she had worked with through the support group. On three occasions, additional family members, who were not available when the family interview was held, were interviewed; these included Aunt P. in the Smyth family, Aunt Choice in the Baker family, and Grandmother in the Myhre family (interviewed by phone). Father Jae participated in the family interview but refused to be interviewed individually stating that it was just too painful to relive the death of Sarah. As well, when I interviewed the Damant family, Brother 2 was present in the home (and assent obtained) and would occasionally come into the room to observe and add a comment, but he was only 10 years old and did not qualify for the study. It is interesting to note that three family spokespersons (Anderson, Schmidt, and Myhre) strongly indicated that Grandfather (maternal) would take part in the study but, when asked to do so, all grandfathers refused, stating that it would be too painful to talk about the experience. As well, five other family members were approached by the family spokesperson but refused to participate (Smyth paternal grandmother, Fraser father, Myhre stepfather, Schmidt Uncle and Grandmother) indicating that to speak of the child's death was just too difficult.

Participant Recruitment and Inclusion Criteria

Following approval from the Research Ethics Board (REB) of my home department (Agriculture, Forestry, and Home Economics-AFHE) and administrative approval from The Compassionate Friends (TCF), I began by recruiting a convenience sample of study participants through advertising at the local chapters of The Compassionate Friends (TCF) (an international self-help group for bereaved parents) via a letter of invitation (see appendix C) and study information sheet (see appendix D) to TCF members. Interested parents were asked to respond to a telephone contact number or e-mail address for further information. Two families (one was a late stage family that was interviewed at the end of the data collection phase) were recruited through this process. I recruited three families through personal and professional contacts. When contact with families was initiated by colleagues, the colleagues offered study information sheets to a family spokesperson, and obtained permission for me to telephone the spokesperson directly. I then telephoned the spokesperson to provide further information on the study and when the spokesperson indicated a desire to participate in the study, I set an appointment time to meet with the family. At the time of this phone call, the family was screened to ensure that they met the inclusion/exclusion criteria. The inclusion criteria for this study were:

1. Participant families had experienced the death of a child as a result of illness or trauma such as accidents.
2. Participant families' deceased child had been 1 day to 18 years old at the time of death.
3. Participant families had been bereaved a minimum of six months with no maximum limit. This minimum criterion was set since the clinical literature suggests that families are often unable to discuss their loss during the period of shock (thought to comprise the initial six months following a death when a child dies) (Rando, 1986;

Talbot, 2002) and that families needed time to establish routines and rituals, issues believed to be important to the phenomenon. Primary informants, those experiencing the death within the previous 10 years, were most actively recruited in initial recruitment whereas secondary informants, those who experienced the death more than 10 years ago, were recruited during the theoretical sampling phase of recruitment. Additional questions were added to the interview guide for these secondary informants including one on their perceptions of the differences in societal norms regarding death and bereavement at the time of their child's death and the current state of these norms.

4. Siblings taking part in the study were required to be a minimum of 12 years old since interviews require a level of reflection and abstraction that may not be possible for younger children (Davies, 1999).
5. Participants were willing to take part in a family interview, as well as an individual interview, (exceptions were divorced participants when other family members refused to participate and one mother whose experience as a bereavement group leader provided verification of emerging themes).
6. Participant families were English speaking.
7. Participant families were articulate and willing to speak of their experience. (N.B. while three brothers (Jaes and Damant) were not articulate, they were willing to speak of their experience and added a dimension to understanding the family experience of bereavement.)

Criterion 1 required revision to capture the perceptions of families who experienced divorce prior to or following the death. This became necessary when mothers were willing to be interviewed but other family members were not (fathers and siblings). After interviewing one family where divorce had occurred (the Bakers) and reported a conflicting experience of family bereavement than intact families, I felt it important to obtain more information on the phenomenon from this perspective justifying the interviewing of only one family member.

Exclusion criteria were:

1. Families who had experienced the death of a child as a result of homicide or suicide were excluded as these causes of death are thought to result in a significantly different bereavement experience for families (Murphy, 1996).
2. Families experiencing death resulting from a pregnancy loss.
3. Families experiencing the death of a child over the age of 18.

Information was obtained on the number and relationship of family members who were eligible to participate. The family spokesperson was asked to discuss participation with other family members who they thought would have understanding relevant to the phenomenon of family bereavement for their specific family. They were encouraged to include all members (including family members of choice) willing to participate. Interviews were scheduled at the convenience of the family.

Further recruitment following the requirements of theoretical sampling

After a general overview of the phenomenon was obtained, theoretical sampling (defined as "sampling on the basis of emerging concepts with the aim being to explore the dimensional range or varied conditions along which the properties or concepts vary") (Strauss & Corbin, 1998, p.73) occurred as I went back to the field to fill in gaps in the data that became apparent in analysis. Of importance in theoretical sampling is identifying inconsistencies and contradictions that may be present in various accounts of participants. By sampling to further explore these inconsistencies and contradictions a fuller understanding of the phenomenon results (Boyle, 1994). This inductive process, one which often poses a challenge to the novice researcher, was done in consultation with my co-supervisors. While ethnography does not require saturation, a term more commonly associated with ground theory, rich and thick data that includes a thorough examination of the context, content, meaning, structures, and actors of the phenomenon was sought and saturation was achieved.

Theoretical sampling of further participants occurred with the help of the bereavement counselor of a local children's hospital and continued word-of-mouth contacts. Accordingly, ethical approval from the Health Research Ethics Board (HREB) and administrative approval was obtained. Theoretical sampling needs were identified and reviewed with two hospital staff members who had access to families on their bereavement follow-up programs; study participants who could add to the breadth of the study. Eight families who had previously indicated their interest in bereavement studies were called by a hospital staff person to inform them of the study and when it was agreeable to them, a letter of invitation (see appendix E) and study information sheet (see appendix F) was mailed to them. One family contacted me via email and was scheduled for an interview. A further seven families that fit the ongoing criteria of the theoretical sampling were then telephoned by the hospital bereavement counselor who was well known to these families. These family spokespersons agreed to receive an invitation letter (see appendix E) and to share it with family members. Four spokespersons indicated to the bereavement counselor that instead of contacting me directly as requested by HREB, they preferred to be contacted by me. I telephoned the spokespersons with all four agreeing to participate.

These four families included three families with surviving siblings who were willing to participate included one sister, two families with grandparents (although all grandfathers refused participation), and two divorced families (one couple divorced prior to the death and one couple divorced following the child's death). Following these additional interviews, I determined in consultation with my co-supervisor's that further theoretical sampling of late stage bereaved families would likely complete data collection as saturation was reached in all other aspects of the phenomenon. The TCF family previously mentioned and two additional families recruited through personal contacts completed the theoretical sampling, as well as verification on the emerging findings.

I anticipated that recruitment would also require obtaining participants through the bereavement follow-up program of the local children's hospital of another major Western Canadian city. Approval from their research ethics board and administrative approval was obtained and the grief counselor sent out three letters of invitation but did not receive any replies. Further recruitment efforts were unnecessary, however, as sufficient data had been collected in the first study site.

Data Collection

Informed Consent

I ensured informed consent through the following procedures. I supplied participants with a copy of the information sheet (see Appendix D and F), at the first interview and answered any questions they had about the study. This information sheet included the study purposes, procedures, my name and contact information, as well as those of my co-supervisors, and institution affiliation. As well, the benefits and risks of the project, together with information pertaining to free and informed consent, were provided including, but not limited to, their right to withdraw at any time from the study, reassurance that non-participation would in no way jeopardize further services from the institution/service from which they were recruited and, and statement of the confidentiality criteria of the study. I explained interview procedures to all family members present. I witnessed the signing of consent forms (general and for photography, (see appendix D and F) by all adult participants before commencement of the first family/individual interview. I obtained assent from all children after the procedures were explained to them by reviewing/ reading of the assent information sheet (see appendix D and F). Both children participating in the study as well as those who were present in the home interview area were asked to complete assent forms. I witnessed the signing of a consent form by a parent for participating children (see appendix D and F). I maintained an awareness that while individuals who are uncomfortable with the sharing of feelings and unable/unwilling to express their current state of grief in a family interview would not be expected to volunteer. When they did participate, however, I paid special care to ensure that their consent was free and willing and to avoid subtle coercion.

Sources of Data and Procedures for the Data Collection Sessions

I utilized multiple data collection strategies in order to gather the diverse perspectives of the participants and to gain a more complete view of the phenomenon of family mourning. Data were gathered through the use of: a) demographic characteristics questionnaire (see appendix A) and genogram (see Appendix B), b) an interview with family as a group, c) an interview with each individual family member, d) photographs of memorabilia that the family chose to share with me, and e) a research journal containing field notes and my personal reflections. An observer was present on three occasions (with the Smyth, Jae, and Schmidt families) and field notes were recorded of her observations during the family interview. As well, following a family interview in which the observer was present audio-taped debriefing sessions were recorded in which the observer and I shared our perceptions of the interview process and participants. While it was proposed that the observer would be present whenever interviews involved more than 2 participants and the family gave permission, the observer was unavailable on the date of the Damant family interview. Further, the observer conducted the family interview and the individual ones with Mother and Father when my own family was interviewed.

Demographic Characteristics Questionnaire, Genogram and "Circles of People Resources"

In order to understand the context of bereaved families, in the first session families were asked to complete the demographic characteristic questionnaire (see appendix A) and a genogram (see appendix B). A genogram is a commonly used exercise in both research and therapeutic settings to identify family structure and relationships between members. It uses standard symbols (circles and squares) to designate family members and a grid to indicate generational relationships. Various family members were identified, including persons who joined the family by birth, marriage, adoption, and choice. Most often three generations were mapped, including members who were deceased, divorced, or no longer involved in the family. This exercise, at the beginning of the session, engaged the family in a non-threatening activity and assisted in building rapport (Nadeau, 1998). Family members conferred with one another during this exercise working together to determine the important persons to be included in this family diagram. It also allowed me to examine differences between families being studied from a structural perspective. During the first family interview with the Smyths, I asked family members to draw lines indicating the strength of their relationships with other family members. Brother Smyth suggested that he might be more frank if he did this in his individual session. Following his advice, the drawing of relationship lines became a procedure at the start of the individual interview.

An additional visual depiction was used beginning with the Myhre Family (family interview 7) which I term the "circle of people resources" (see Appendix G). I realized that the genogram suggested blood and legal relationships and was less useful for exploring family members' definition of family during their bereavement. I devised the following procedure: a) in the individual interview, the participant was given a piece of paper with a circle containing the word "Me", b) after a very brief explanation of Hill's concept of resources during stressful events, the participant was asked to list their "resource of people" putting the name or relationship of the people most supportive to them in the inner circle, c) then adding concentric circles to indicate those persons of decreasing support in their network, d) the participant was then asked to circle the names/relationships he/she considered family. As a final step, the participant was asked how he/she decided who was to be circled (who was family and who was not), hence arriving at a clearer definition of family for each participant.

Family Interviews

Interviews allowed participants to tell their stories, thereby offering them a way to make sense of their situation. In the research setting, the interview is considered a conversation with a purpose, and encouraged participants to describe, in depth, their experience of the phenomenon (Marshall & Rossman, 2006). Each family was invited to participate in an audio-taped family interview which on all but one occasion (Baker family) took place before the individual interviews. On all but three occasions interviews were conducted in the family home. On one occasion the participant was in the process of changing homes and chose to be interviewed in my office (Barnes family). On the other occasions, the couple had long since divorced hence no commonly-held family home was intact; one couple choose to be interviewed in my office (Baker family) and the other participant in my home (Stewart family).

This unstructured interview began with the grand tour question (see appendix H), 'Could you tell me about your family?' Grand tour questions offer a general description of the phenomenon of interest along with elements of the context (Spradley, 1979). The next questions 'Could you tell me briefly about the circumstances of (name) death?' and 'What was your family like before (name) died?' were used to gain an understanding of the family culture before the death, as well as the events surrounding the death. Further questions related to the family's routines and rules, their use of family celebrations/rituals, and the family's support system were asked as needed to focus the interview on the specifics of grief and mourning during family bereavement. The fourth question, 'What is your family like now following (name) death?' was asked to obtain information on changes in activities/routines since the death. As this interview concluded, each family member was asked to comment on one aspect of their experience that they believed to be most important with the question, 'What would be one thing you want others who are new to the loss of a child (or brother/sister) to know about this experience?' At the conclusion of the interview, I asked to view the family's memorabilia of the child. On some occasions, this necessitated visiting the child's previous school to view a tree/bench. Mother Barnes brought a photograph of her daughter to the interview in my office, but I did not photograph this. As well, Father Stewart has no memorabilia of his son. Following the first interview, I analyzed the data collected in order to discover questions from that data to ask in future interviews (Spradley, 1979).

When distress in a family member was noted, I inquired if the family wanted to take a break or if the interview needed to be stopped. In no cases was that necessary. I paused the recorder on a few occasions to allow family members to compose themselves. In this way, I demonstrated respect and sensitivity for the very personal stories that were being shared.

Family sessions ranged from 2 ¼ to 4 ¾ hours with the interview ranging from 59 minutes to 1 hour 55 minutes. All families were able to answer the questions outlined earlier and completed the demographic characteristics questionnaire and genogram in the initial family interview. I then scheduled individual interviews with family members (with the exception of the Baker family who had already completed their individual interviews) and provided family members with a list of community resources should they require support due to distress from taking part in the study (see appendix I).

Following the initial family and individual interviews, I conducted data analysis and wrote a story of each family, based on the data collected during the family and individual interviews. Prior to a second family interview, the family story was mailed to each family member with an explanatory cover sheet. In the case of the Smyth and Myhre families, some information arising from individual interviews had not been revealed in the first family interview. In order to honor the confidentiality of participants, in the case of the Smyth family, the story was divided into its component parts and family members only received their part for first review. When all family members gave permission for their part to be shared with other family members, the story was reconstituted and redistributed to all family members. In the case of the Myhre family, Sister Myhre was telephoned numerous times and messages left but no reply was received. A phone call was then made to Mother to request that Sister contact me but Mother informed me that since the anniversary of Ray's death was imminent, Sister was too stressed to reply. Since permission was not given to include the confidential information in their family story, it was excluded and a revised edition was sent.

Following the distribution of the family stories, I arranged and held the second family interviews. Not all family members choose to be present at the second interview. At this interview, I reviewed the family story with those present and my visual representation and explanation of my emerging ethnography of family bereavement was reviewed with them. Participant's responses to my visual representation were audiotaped. Following this session each family was sent a thank you card and small gift.

Individual Interviews

As Charmaz (2004) suggests, interviews make public what are often private thoughts and behaviors, but the stories of some family members may be silenced when there is more then one storyteller. I was unable to find any recommendations in the literature regarding the preferred order of the individual and family interviews. The family spokesperson (the participant making first contact with me) was given a choice of timing, but only Father Baker choose to be interviewed individually first stating that he wanted time to "dredge up old memories" on his own before engaging in a family interview. Most often family spokespersons stated no preference and then I choose to conduct the family interviews first since I thought it provided me with a clearer view of the family and the context of the child's death without the need of each individual to repeat this information.

Family members were invited to participate in an individual interview at the conclusion of the family interview, thereby, giving them the opportunity to voice their private thoughts. Since in most instances informed consent had been attained in the family interview, individual family members were simply reminded that they had the right to withdraw from the study at any time and that should they feel unduly distressed following the interview, they should phone me and resources would be provided for counseling.

Individual interviews of family members generally took place in the home of the family member. However, Aunt (maternal) Smyth, Grandmother Smyth, Father and Mother Baker, chose to be interviewed in my office. Mother Jae was interviewed in her art studio, and Father Smyth, Aunt Choice Baker, and Father Stewart were interviewed in my home.

The individual interviews began with the family member completing the relationship lines on the genogram, followed by the circle of people resources diagram (Families 7 through 12). Children were given the option of telling their story by way of drawing or story writing but none choose to do so. The audiotaped, individual interview then began with a focus on the family member's experience of grief by asking participants to define the terms grief, mourning, and bereavement followed by the grand tour question (see appendix J) "Could you tell me what it was like for you when (child's name) died?" The goal of these interviews was to discover the individual's experience of this defining event including the thoughts, emotions, and behaviors that had been part of their process of mourning and grief (Nunkoosing, 2005). Further questions included, 'How do you think your family has influenced/ been influenced by your individual experience of grief?' At the end of the interview the family member I asked, 'Is there anything else you want me to understand of your experience that we have not talked about?' thereby attempting to uncover the uniqueness and boundaries of the individual process of grief when a child dies.

Field Observation

While in a focused ethnography fieldwork may be omitted (Morse & Richards, 2002), in this study I made note of observations of the family's patterns of interaction and mourning behavior during each family session. To further enhance the collection of observational data, on three occasions when more than two family members were present and it was acceptable to the family, the observer was present during family interviews. She focused on the interactional patterns and behavior of the family. The additional data thus collected enhanced these field observations as I was able to more closely attend to the speaker while the observer recorded interactions between the non-speakers. Mansell, Bennett, Northway, and Mead (2004) recommend using an observer when conducting focus group research in order to gain a fuller recording of the action of the interview. The observer in this study contributed useful information in the analysis by recording the details, including any discrepancies the interviewer may not have noticed in the interview setting. Participants very willingly agreed to the observer's presence. The data was enriched by her observational field notes (see Chapter 6). Field notes were recorded by this observer and audio-taped debriefing sessions took place between the researcher and observer immediately following family interviews.

While it was proposed that I would observe families while they engaged in remembrance activities, such as visits to the cemetery or gatherings for birthdays or anniversaries, no occasions presented themselves during the study period.

By interviewing families in their homes, I had the opportunity to view and photograph (with their permission) family mementos of the child and to learn how these items were used by families in their mourning. These observations of photos and other memory items (sometimes including the urn holding the child's ashes) gave me further opportunities to understand the importance and the contribution of these mementos to the family's bereavement. A more complete sense of the family's experience was apparent when these items were unavailable for viewing (Barnes and Stewart families).

The Researcher's Journal

A journal was kept to record field notes and my personal reflections (researcher's diary) on the research content and process. The observer, as well, contributed field notes to this data source.

Field notes. Focused ethnography also requires researchers to record observations and descriptions in their field notes—a detailed, nonjudgmental, concrete description of what has been observed (Knoblauch, 2005; Marshall & Rossman, 2006). After each interview, operational, methodological and reflexive field notes were typed and entered into the family's computer file so that these could be added to the interview transcript and coded as required. Operational field notes recorded the date, locations of interviews, the people present, their spatial distribution in interactions, and other pertinent practicalities of the study, as well as other details that I believed were important to the observations being made, such as pauses in conversation, and behaviours of participants (Mayan, 2001; Palys, 2003). Impressions of the interview themes and my reflections on the experience and any impact I felt I was having on the participants were also recorded. When the observer was present, additional field notes were recorded by her and an audiotape of the debriefing session was made.

Methodological field notes recorded the ongoing process of this study. A handwritten researcher's journal was kept throughout data collection and analysis to record the theoretical and coding decisions that were made in the course of the study (Cutcliffe, 2003). These included notes on the changes to the guiding questions, discussions with my co-supervisors on procedural issues, and my own reflections and questions on the unfolding study. Through these notes a decision trail and the means for tracking the knowledge and understanding of the situation over the course of the study can be seen.

In addition, theoretical notes were recorded to elaborate on the relationships within the data and as a means to record particular interpretations while noting discrepancies and inconsistencies within the data and guiding me in further data collection (Hammersley & Atkinson, 1995; Morse & Richards, 2002). Often these notes were recorded during audio-taped sessions with my co-supervisors. During data collection, biweekly debriefing sessions were held with my co-supervisors to review the emerging data analysis and provided me with the opportunity to ask questions on theoretical and methodological issues of data collection and analysis.

The researcher's diary. A research diary was used to record my theoretical and reflexive field notes. These "private conversations with self" (Charmaz & Mitchell, 2001, p.167) were used by me to record my personal responses to the data collection process aiding in my reflexivity. This diary also recorded my beliefs, values, and personal responses to the interviews and research process.

Data Analysis

Analysis commenced as data was collected (Hammersley & Atkinson, 1995; Morse & Richards, 2002) and audiotapes transcribed. "The main goal of most ethnographic research is what has been classically termed thick description (Geertz, 1973): a narrative that describes richly and in great detail all features of the culture" (Morse & Richards, 2002, p. 52). This inductive, iterative process began with the data of the first interview and continued as each consecutive interview provided data which were compared with previous interviews in a process of analysis that evolved and allowed an interpretation of the phenomenon of family bereavement (Creswell, 2003). Following the first interview I analyzed the data collected in order to discover questions from that data to ask in future interviews and continued this process throughout data analysis of each new transcript I read (Spradley, 1979). As Hammersley and Atkinson (1995) suggest there is a dialectical interaction between data collection and data analysis that requires reflexivity. I spent many hours thinking about and reflecting on the data and their significance to my understanding of family bereavement.

Data Management

In order to begin data analysis, the audiotapes of the family interviews were transcribed verbatim and field notes—describing the setting, movement, and interaction of family members, facial expressions, and other observed features—added to the transcription. Transcription required me to address the question of what was needed in transcribing and, in this study, I decided to add linguistic features such as "ums" and "ahs", as well as nonverbal data such as pauses and crying as recommended by Knoblauch (2005). Notes were added when activities in the environment disturbed the flow of the interview (ex. phone ringing) or quality of the recording (background noises). I cleaned transcriptions of the interviews increasing the accuracy of the interview transcript. Operational field notes were combined with the interview transcript in preparation for analysis. Interview data was entered into NVivo Version 7 (QSR, 1999-2007), where it was later coded and codes combined into categories. Photographs of memorabilia (labeled with the family name) were downloaded on to a password protected portable hard drive reserved for the study data. Identifying information including consent forms, genograms and circle of people resources when they contained family member's names, and contact information were kept separate from the printed copy of the transcribed interview which was placed in a colored folder and separate plastic envelope for each family.

Analysis

"Analysis proceeds from the ground up. Data are raised through increasingly abstract levels of conceptual analysis" (Charmaz & Mitchell, 2001, p.167). At the start of this analysis, the guiding questions were:

1. What are the integrated and coherent family stories reflecting each family's experience including:
    a. What were the beliefs, norms, roles, and behaviors of this family before the death occurred?
    b. Have these beliefs, norms, roles, and behaviors changed following the death?
    c. What were the routines of families before and after the death? Have they changed over the bereavement?
    d. Does mourning involve the use of rituals within this family?
2. What are the experiences of grief and mourning of the individual family member during bereavement? Does this experience differ based on the relationship with the child?
3. Is the grief and mourning of the individual family member influencing and/or being influenced by family beliefs, norms, roles and behaviors during bereavement?

Further questions that guided analysis as data analysis proceeded were:

4. Do families/individuals experience an adaptation during bereavement? If so, how can this be described?
5. Are the beliefs and norms of the family before the death of the child affecting the grief, mourning, and adaptation of the individual and family during bereavement?
6. When families are divorced, or divorce shortly after the death occurs, are their experiences during bereavement different from those who do/have not divorced?
7. In what way can the family experience of bereavement be described as family work?

Data analysis included both within-case and across-case analysis. Family and individual data were coded separately and then within each case (family) the parallel processes of individual and family bereavement were woven together into a coherent family story (within-case analysis as seen in Chapter 5). Across-case analysis involved seeking common themes among the family participants. These results are presented in chapter 6. The following steps were used in analyzing the data:

1. I read each of the family transcripts twice and listened to the audio recording in order to become familiar with the data and identify key concepts in each transcript. This immersion in the data allowed me to understand what was happening, to examine ideas and suggest actions for further data collection, and to begin to develop a theoretical understanding of family bereavement (Marshall & Rossman, 2006; Morse & Richards, 2002). By listening to the recording, I was able to understand more fully the exchanges between family members, as well as the family tone and how my questioning varied in response. A similar procedure was followed for the individual interviews. After the first 6-8 interviews I did not find it necessary to listen to the entire interview to understand my approach in the interview and for the remaining interviews only the first 10-15 minutes of the interview were listened to twice.
2. For the first five families when all transcripts of family and individual interviews for a given family had been read at least twice, I wrote the initial "family story" utilizing my conceptual framework sensitizing concepts as a beginning point (Hammersley & Atkinson, 1995). Hence, I focused on family member's reports of the family norms and beliefs, roles and routines both before and after the death. As well, I considered other events that were occurring at the time of the child's death and the reports of family members on their patterns of coping. As they spoke I became aware of the behaviors of loss/restoration orientation they described and their movement back and forth in this process. I was keenly aware of the differences in the family/social support networks that various families were describing and the effects this seemed to be having on their experience of bereavement. In these initial stories, I recorded not only my overall impression of the experience but I found the need to include my own reaction to it. This process began the "within case" analysis in which data was analyzed to identify family patterns unique to each family and took into account data from both the family and individual interviews. I recorded reflexive notes in researcher's diary regarding the impressions I had of the family's pattern of interaction as seen in the family interview and the roles individual family members played in the family. I made further entries regarding the differences family members reported in the family interview versus their individual interviews and my perceptions/understanding of these differences. During this story writing, I became acutely aware of the differences and uniqueness of each family story, but I was not yet able to see

commonalities across families or across the roles played by family members (i.e. I was not seeing mothers having similar experiences).

3. For the first four families (19 transcripts) open coding of each transcript was done on a phrase by phrase basis using the interviewees' own words as much as possible on a printed copy of the transcript. These codes were transferred to Post-it Notes® and sorted into categories on large sheets of paper with separate sheets for each family in the first coding/categorization. Coding and this initial categorization of these transcripts were reviewed with my co-supervisor (JS) who is experienced in qualitative methods. During this review it became evident that families were describing similar catergories but the data was difficult to manage on this paper and pencil method and I decided a computer data management program would make the task more manageable. Each transcript was then entered into Nvivo as case files. The codes from the eight transcripts of the Smyth family were entered as free notes and collapsed into categories within tree notes. Categories and subcategories from the family interview (e.g. about the child, about the death, communication, dynamics including letting the child go, separate ways to grieve, etc.) generally differed from the categories and subcategories from the individual interviews (e.g. feelings, cognitions, things found to be helpful/of hindrance), but some overlap was seen in categories (funeral events, timing, employment, relationships with other family members). Since codes were already present on the printed transcripts, these codes were entered into the categories with new categories added as needed (N.B. A complete clean transcript of each interview was always kept as a Word document for reference purposes.)

4. Coding proceeded for family 6, 7, and 8 in the same manner with new tree notes entered as needed to fit the coded data. I kept theoretical notes in my journal during this process but it became increasingly difficult to make sense of the data using this method. In a consultation session, my co-supervisor (JS) suggested charting each family member's experience of bereavement on large pieces of paper in hopes of revealing some commonalities as well as uniqueness. (codes from each transcript were recorded in a different color for each family to facilitate distinctions between individual and family codes.) Through this process new categories arose, especially in the family interview data. As a result, each family interview transcript was re-catergorized into 19 categories (with 12 of these categories having numerous subcategories). Some categories (support network,

beliefs, communication) stayed the same while others were collapsed and renamed to reflect the emerging conceptual understanding of the data (remembering, reminders, routines, stories of the child, spirit of the child, meaning making). Individual interviews were still coded into the original categories as this data appeared to have fewer new categories emerging. I then began rewriting the family stories using categories from both the individual and family data. The remaining five family transcripts were coded first on the printed copy and then categorized into this new scheme. The new categorization was shared with my co-supervisors in an effort to enhance the validity of the categorizing process and to guard against bias (Burnard, 1991). For this categorization a case was defined as the family unit. Transcripts of the individual interviews were re-read to determine if further data had been provided that fit with these categories. In this way both within case and across case analysis was accomplished. During the within-case analysis and writing of these new family stories, I began to recognize connections between the family and individual categories and became aware of the emerging themes in the data. A process was evident in each family story.

5. A further review of the categories revealed emerging themes from which I began to create a visual representation of the process of bereavement at both an individual and family level. This led to my emerging ethnography of family bereavement. During the course of the seventh and eighth interviews I became aware of the description of family 'work' that participants were describing. As I reviewed the themes within the visual representation, I recognized that the main theme to emerge from both individual and family level data was that of 'work'. Through identification of this theme, I was able to understand that 'work' for the bereaved family occurred as a family process and as a function of support. I added a further question to my interview guide for families 9-13, "Would you say what your family was doing during this time was 'work'?" proceeding the question with a short explanation of what I meant by family 'work' (maintaining the household, caring for children, giving emotional support and maintaining relationships through listening to and comforting each other.) I maintained theoretical notes in my journal throughout this process.
6. Following the identification of these themes and the emerging ethnography, each transcript was reread, working through the list of themes to ensure that all aspects of the interview had been considered. All transcripts (both family and individual)

were reentered into new NVivo tree nodes representative of these themes which included: creating space, defining family, family functioning, family work, loss and restoration, loving acts, meaning making, reformulating (enduring, suffering, family, self), sharing the story, spirit of the child, support (family, social network), and time. I continued to write family stories reflecting these themes and identifying the theme that was most representative of the family's story. Through both across-case analysis, together with the within-case analysis family stories, I became aware of how bereaved families make up a cultural group.

7. I mailed a copy of the family story to the participants and asked them to check that the story was an accurate representation of their perception of their experience. Often family members found the intensity of these stories difficult to read, with one father remarking "You live it, you talk about it, but when it is in black and white it seems so much worse." In all but one instance only minor changes were requested. One mother asked for the story to be rewritten to reflect her relationship with her surviving son more accurately. During the second interview it became apparent that in first telling of her story at a time that was approaching the anniversary of her daughter's death, she concentrated on her daughter's death and spoke very little of her son. This gave a very different and inaccurate understanding of her family than was revealed in the second interview. Following this second interview I rewrote her family story, mailed it to her, and she then agreed it was a correct account of her experience. A number of participants asked that words and phrases such as "you know", "like", "um", and "ah' be discarded from quotations and this was done when the meaning of the quotation was not changed by doing so. In the second family interview, my visual representation of family bereavement was presented to the family members in attendance for verification of the themes it contained. Field notes recorded participants' comments on the themes and the representation. All families reported agreement on the themes with many remarking that the visual representation clearly presented the process of individual and family bereavement. One father, whose family had not engaged in family work, pointed to the gear representing loving acts and remarked, "This is what stopped with us. We no longer did loving acts for each other." This data was further analyzed in conjunction with my supervisors.
8. Genograms were studied to obtain information on the context of each family and to determine similarities and differences among family units. "Circle of people"

resources were studied to obtain information on how participants defined family in the context of bereavement for the loss of a child.

Reflexivity

Research is engagement—questions are as much about the researcher, as they are about the phenomenon being studied (Palys, 2003). When the researcher is investigating a phenomenon that is close to her own setting, distinguishing her perspective from that of participants is crucial and a difficult thing to do. The researcher may not always be aware of the assumptions she makes based on her own cultural background, but it is imperative for her to examine assumptions (Morse, 1992). It is this examination, which is termed reflexivity—"the capacity to reflect upon one's actions and values during the research, when producing data and writing accounts, and to view the beliefs we hold in the same way that we view the beliefs of others" (Arber, 2006, p.147).

As a mother who has experienced the death of a child, I have experienced bereavement when a child dies. As a clinician who has worked with many bereaved families, I have heard the painful stories of loss and the efforts the individual makes to heal this pain. In order to thoroughly understand my assumptions and biases, before commencing this focused ethnographic study, I took part in an individual interview. My own family was interviewed followed the Smyth's family interview due to some scheduling delays with other family members and the observer who conducted the interviews. Being interviewed, considered a valuable source of insights for the researcher and thought to facilitate reflexivity, was a difficult process since these issues had never been openly discussed in our family. I found that the interview brought forward painful memories about our family functioning and how it affected my experience of family bereavement. I have recorded reflections in my research diary on interview experiences and of the assumptions I have made about family bereavement as a result. Before undertaking this study, as part of a course in family theory, I wrote (and re-read) an essay on my assumptions and beliefs about family bereavement. This essay was used on an ongoing basis as an additional check on my assumptions and biases.

Throughout the study, I maintained a research diary to record my reflections on the research experience, including my reactions to participants' stories. These reflections encompassed both my emotional reactions as an observer as well as my theoretical assumptions based both in the literature and my clinical experience. Field observation required conscious work to understand the transformation that went on in the research experience and how my presence affected the story that was being told (Arber, 2006). I noted these observations in my research diary as well. This process of reflection was a moving "back and forth in a kind of dialectic between experience and awareness…to identify the lived experience that resides in the space between subject and object" (Finlay, 2002, p.533). I also recorded in my research diary my motivation, assumptions, and interest in the research topic and shared them with my mentors in order to maintain an ethical position with study participants.

Rigor

Rigor is what makes a research study solid and credible. In quantitative studies it is commonly referred to as reliability and validity of the study, while in qualitative methodologies it takes on various terminology (Morse & Richards, 2002). The approach of verification strategies (Morse, Barrett, Mayan, Olson, & Spiers, 2002) was used in this qualitative study to examine the important issue of rigor. "Verification is the process of checking, confirming, making sure, and being certain. In qualitative research, verification refers to the mechanisms used during the process of research to incrementally contribute to ensuring reliability and validity and thus the rigor of the study" (Morse et al., 2002, p.9). The method of verification strategies involves an iterative, self-monitoring, and self-correcting process. These strategies include issues of concurrent data collection and analysis, investigator responsiveness, methodological coherence, sampling, theoretical thinking, and theory development (Morse et al., 2002).

To maintain the rigor of this study, I:

1. maintained concurrent data collection and analysis throughout the study. In this iterative process, I participated in "forms of mutual interaction between what is known and what one needs to know" (Morse et al., 2002, p.12).
2. addressed investigator responsiveness by maintaining a creative, sensitive, and flexible approach to the data. Researcher sensitivity and flexibility is seen in my research's diary where I recorded my reactions and impressions as data was collected and analyzed (Boyle, 1994). I also discussed these reactions and impressions on an ongoing basis in mentoring sessions with my co-supervisors throughout the study. I remained open to emerging data that did not fit with previous conceptualizations. My theoretical field notes recorded the changes in data collection and analysis that were required as a result of these discussions and responses.

3. addressed methodological coherence throughout the research process by maintaining methodological field notes in my research journal. As well, biweekly supervisory meetings during data collection and analysis ensured that issues of research methods were regularly addressed in this study.
4. conducted theoretical sampling, as described in a previous section, to ensure that sufficient and appropriate data were obtained to account for all aspects of the phenomenon.
5. kept theoretical field notes to demonstrate my theoretical thinking as I recorded ideas that emerged from the data and confirmed these ideas in the continuing data collection. As well, the field notes recorded the process of theory development as I moved , "with the separation between a micro perspective of the data and macro conceptual/theoretical understanding" (Morse et al., 2002, p.13).
6. Further, I presented my emerging themes to a professional colleague who is well versed in the issues of family bereavement. She agreed with my conceptualization. I also presented my visual conceptualization and emerging ethnography at two conferences and to a research group of which I am a student member and received positive feedback on my work.
7. As well, I presented my emerging ethnography, including my visual conceptualization, to study participants to confirm that it fit in with their perceptions of their experience of family bereavement and they agreed it did.

From a constructivist perspective (Charmaz, 1990), reality emerged and was shaped by the social interactions which took place between me and the participants. As such this reality was verified through each step of this research study as data was shaped by the interactions being studied as well as by my analysis as revealed in the final ethnography (Hammersley & Atkinson, 1995).

Ethical Issues

This study was submitted for ethical review by the University and healthcare institutions. The following are the main ethical considerations within the study (a) the vulnerability of the research sample (risks and benefits), (b) confidentiality, (c) autonomy of participant involvement, and (d) informed consent (which were previously reviewed). Spradley (1979) reminds us that participants do not necessarily hold the same values and beliefs as the researcher, therefore, the researcher must remain ethical and respectful of participants throughout the research process. Additionally, Nunkoosing

(2005) reminds researchers that power can be an issue in conducting interviews in that the "interviewer rests in his or her authority as a seeker of knowledge and methodological expertise, and that of the interviewee as a more or less privileged knower" (p.699). Further, Ninkoosing reminds the researcher that consent is the participant's civil right and I must not unduly persuade them to agree to or resist our request for free participation. Since interviews are conducted and stories told in the moment, neither the interviewer nor participant can predict what will be said. Therefore participants must have the right to remove part or all of what they have said from the study. As well, the researcher cannot predict what the experience of the participant will be and must stay alert to participant distress and not promise that participation in the study will result in a beneficial outcome (Nunkoosing, 2005).

Bereaved families are considered to be highly stressed and research methods must minimize these stress levels. Distress may be increased for family members when they are asked to recall their experiences of loss. It is interesting to note, however, that two studies (Dyregrov, 2004; Kreicbergs, Valdimarsdottir, Steineck, & Henter, 2004) found that while most parents found it distressing to review the death of their child, most reported that this distress was short lived and 99-100% found their participation was a positive or very positive experience. In my study, two participants provided evidence to support these conclusions. Mother Fraser stated to me that she appreciated the opportunity to speak about her bereavement experience and to share her memories of Neil. Brother Smyth provided even stronger evidence when he wrote me a note that indicated that the interview experience had caused him to re-examine his life and encouraged him to "move on."

Another common problem in family interviews is that the family member may feel compelled to reveal feelings and information previously unknown to other family members (Daly, 1992). Participants were cautioned at the beginning of the family interview about this risk and were encouraged to share only what they felt was appropriate with the intention that no undue stress would be created by my probing. During the individual interview with Grandmother Anderson, I took direction from her level of distress knowing that it could mean that the interview would not be continued and data lost. In this instance, where such action was needed, she chose to continue (after a two-minute pause) and her distress decreased over the course of the interview.

Risks and Benefits for Vulnerable Participants

In order to address this ethical issue, I:

1. Provided participants with an information sheet outlining the risks and benefits of the study and a list of community services should the participant feel distressed.
2. In the event that a participant became distressed during the interview, the tape was paused, and I asked whether he/she wanted to continue after the pause, the answer was always yes.
3. After the interview when the recorder was turned off, I inquired how the participant(s) found the experience. When I recognized that participants were experiencing some distress, (due to my training and qualifications in counseling), I debriefed the interview experience with participants. These sessions lasted from 10 to 45 minutes. At the termination of the debriefing, participants were reminded of the community resources available to them should they require it.
4. I telephoned participants the day after the interview to inquire about the level of distress when it had not completely abated during the debriefing. On no occasions did participants report the need for assistance with the distress during these phone calls although participants were reminded that follow-up care was available through community resources.
5. No participant appeared to experience an overwhelming level of distress during the interview process (i.e. suicidal ideation). No evidence of abuse of a minor was disclosed.

Autonomy

To ensure autonomy, I:

1. Assigned a pseudonym (chosen by the family) to each participating family and for each child. Interview data was identified only with this pseudonym and relationship to the deceased child (ex. Mother Smyth) to assure anonymity.
2. Participants were given contact numbers so that if they desired to have their information not included in the study in the first two weeks following their participation in the study, materials would be removed and kept in a sealed envelope separate from study materials. However, participants were informed that because of the nature of ethnography, after that date data may already have been analyzed and consequently would be unable to be removed from the study. Further, this risk was explained to participants in the information sheet (Spiers,

2005). No participants chose to discontinue their participation in the study.

Confidentiality

I am bound by confidentiality criteria under university policies and my professional code of ethics. To ensure confidentiality, I:

1. maintained awareness that when research is conducted in the family's home possible violations of privacy could occur. I was cautious to maintain the boundaries of the individual's confidentiality. Participants may feel comfortable and safe in their home environment leading them to share more than they had originally planned (Daly, 1992).
2. will, on completion of the study, store all data in a locked file cabinets designated for this purpose and maintained as guided by university policy, in sealed envelopes clearly marked with study name, name of researcher, and dates of study. Informed consent for this study has provided for the secondary analysis of the data.
3. will store the list of participant's names, contact information, and consent forms in a locked cabinet separate from study material while the study is ongoing.
4. informed participants in the family interviews, of the issues of confidentiality and asked them to keep the information private with a statement such as 'What is said in this room, stays in this room.'

CHAPTER 5

FAMILY STORIES:

FINDINGS FROM WITHIN-CASE ANALYSIS

In this chapter I will present my findings within-case analysis used to construct a coherent story of bereavement for each of the 13 families who took part in the study. Narratives are a useful way to "bring order to disorder and find meaning in the meaningless" conditions so often thought to be associated with the death of a child (Gilbert, 2002, p.223). These narratives are the product of comparing and contrasting individual family member's experiences with each other and with those related in the family interviews. Participants spoke in the interviews of process at both the individual level and the family level. Further, when they spoke of the family process they described two aspects. One aspect was where family members created an experience which was greater than the parts that occurred during their individual process. The second aspect of the family process occurred when family members supported each other in a variety of ways including doing practical tasks, listening to, and being present for one another, and accepting the differences in each others ways to mourn.

The goal of this analysis was to construct a narrative for each family. This was an iterative process wherein the within case analysis was done alongside the across-cases analysis, hence, the stories reflect the categories and themes that emerged from the across-cases analysis. As well, these stories incorporate the observational data recorded during the family interviews which reflected the process they used to construct their story (Rasher et al., 2000). During the family interviews, variation was seen in family communication – for example, who spoke to whom and when, nonverbal communication used, and what topics were discussed. During individual interviews, some members expressed thoughts they felt would be unacceptable to reveal during the family interview but which they believed were important for me, as researcher, to understand. In order to maintain participant's confidentiality, this added information could not always be revealed in the family story but has been included in the across-case analysis where anonymity could be maintained. This reality reflects a methodological challenge to studies using family interviews. On two occasions, in particular, I found myself wrestling with the difficulty of maintaining participant's confidentiality while aiming to create a true representation of the family's experience of bereavement. When the information was crucial to understanding family bereavement, I sought and was granted permission by the individual to include these personal thoughts.

The findings of the within-case analyses reveal family stories with varied trajectories. In some families, grief and mourning appeared as primarily an individual experience. Most notably this occurred in families where divorce occurred shortly before, or after, the death of their child. However, while listening to family members (individually and as a group), relate their experiences I became aware of the energy required to grieve and mourn. I labelled this bereavement as work— defined in common usage as "activity in which one exerts strength or faculties to do or perform something; sustained physical or mental effort to overcome obstacles and achieve an objective or result" (Merriam Webster, 2004). Each story demonstrates the work family members do both individually and, most often, together as a group. This work includes not only their individual work to deal with their own loss, but also their work to support other family members during bereavement.

In studying family bereavement I became keenly aware that it is an experience that takes each family on its own journey over time. As Stroebe and Schut (1999) suggest, it is a journey that oscillates back and forth from experiences that are rooted in the pain of loss to those where families work hard to restore aspects of their "normal" life. During analysis, I became aware of this "loss versus restoration orientation" with numerous individuals speaking of the triggers that influenced their move from one orientation to the other. However, it appeared that this was difficult work to do and listening to it reminded me of the theory of enduring/suffering introduced by Morse and Carter (1995). In this theory, enduring is referred to as "the capacity to last, to get through, to survive an experience or an intolerable situation" and suffering as "work, an all-consuming endeavour that one must experience to work through the event (p.40). . . .the emotional response to loss" (Morse & Carter, 1995, p. 39). Enduring was further conceptualized as enduring to survive and enduring to live; it is this later concept that seemed to resonate in the experience of family members as they sought "to get through' the day and accomplish the tasks necessary to maintain at least some semblance of family life. I labelled family members' individual work of coming to terms with their loss describing this process as referred to in this theory as "self-reformulation" a process of valuing suffering, re-ordering priorities, and giving back (Mayan et al., 2006). For me, the terms enduring and suffering are powerful and seemed to fit with the experiences being described by these family members. I shared these terms in second family interviews with my participants and found they resonated with them as well. Therefore, it is appropriate to use these terms in the following stories.

The stories reveal that families and family members are changed by the death of their child. For some families, the changes that occurred in individual family members meant that the family could not be sustained; divorce resulted. Other families reported the establishment of stronger and closer bonds between members. Those families who had experienced the death of a child many years ago, say that this change is fundamental and forever. These families suggest that there is a point where they recognize that they are a new family, unlike the one they were before; stronger because of the ongoing presence of their child.

Each family story will begin with a brief analysis of the observations during family and individual interviews, followed by the child's story describing who s/he was in the family and what her/his place is now. In this story, the child's nature and personality, the roles s/he played within the family, and the ways in which the families remember the child will be discussed. Following is the family story including a description of their norms and beliefs before the death occurred and their experiences during bereavement. Themes that emerged in the process of across-case analysis are often included in the narrative. These themes include family antecedents (norms, roles, routines, shared beliefs), family grief (quieting), family mourning (telling the story including creating spirit of the child, rituals, and meaning making), and restructuring (changed roles and routines, place for the child). These themes link the family stories (within-case analysis) with the findings described in the next chapter (across-case analysis).

In order to understand the common processes that occur during family bereavement, the stories of my thirteen family participants will be presented in the order of where they are in the process of creating a new family. Direct quotes of participants are recorded in italics. Participants restarts, and sounds like "um" and "ah" have been eliminated to enhance the fluidity of the story themes. Ellipses indicate omitted parts of the sentence that would not add further meaning.

The Family Stories

The first four stories in this within-case analysis reveal the 'individual work" of family members without the presence of "family work" within the nuclear family and often with little occurring in the extended family. However, as may be seen in some stories, family members relied on, or created a family of choice, to aid them in their work during bereavement. Three of these families experienced divorce following the death of their children while one couple had divorced during the illness of their child. In all cases, family members discussed how their own grief and mourning was addressed in spite of the "family work" being unaccomplished.

The first story is about the Barnes family. It is told only by Mother because her family is still adjusting to the separation and divorce of Mother and Father that had taken place shortly after Clare first became ill with leukemia. During this illness, Mother and Father struggled to adapt to life with an ill child and, ultimately, could not maintain their family. Their work of redefining family after this loss was still in progress when Clare relapsed and died. At the time of the interview, the family did not share stories of Clare. As will be seen in the family story, Mother and Brother speak very little of Clare, hence telling her story is done by Mother alone. This leaves the story without the perspectives of Brother and Father and the work they are doing to adjust to life without Clare. It appears in Mother's telling of the story that Father spends time between suffering and enduring, while it appears Brother endures perhaps as his way of protecting his parents from further pain. However, the Barnes family appears to be one where the work of grief and mourning is done by individuals with little evidence of family work evident in the interview. At this time, just one year after Clare's death, it appears that the family is struggling to define itself. Perhaps without a clear definition of who is family, "family work" of bereavement is not possible within the nuclear family and can take place only as limited support from the extended family.

"Life is a series of grief and mourning"
Defining Family through Multiple Losses
The Story of the Barnes Family

Telling the Story: The Spirit of Clare

When the tiny, premature little Clare was born with Down's Syndrome, Mother was afraid of her little daughter. She says, *"It was hard for me to bond with my daughter when I first had her. I wasn't ready for the bond. She was 11 weeks premature and in hospital for quite a number of weeks. . . .I couldn't breast feed her. The bond came. . . after--I loved her. I could tell she had personality right from the get go even though she was teeny weeny, she was going to be special. But I think the real bond, where how I felt with my son happened, came around her first birthday".* Father accepted Clare and her disability quickly and convinced Mother that Clare "*was a baby and you're going to love* *her like any other baby. He accepted her disability quicker than I did. It took me definitely longer because I think I'm stuck in a perfect family world at that point. I had my boy and I didn't think I would have a daughter with a disability."* Mother *"mourned the death of my typical little girl at that point"* and the bond between them took longer to form as a result of her grief.

Due to her disabilities, Clare *"was a baby longer. She was a toddler longer and she demanded more time."* She needed more of Mother's care than Brother had. Mother learned, *"I ended up loving her . . . because she needed me. . . .I had to advocate for her and defend her and I was there for her. And in the end, it made me love her. . . . The work that it involved to do some of the things and it just, that bond just got stronger and stronger throughout the years for me. . . after getting to know her, love her, and cherish her, I felt guilty . . .(but realized that this was) probably a common emotion for people to feel dealing with the disability."*

When Clare became ill for the first time, she took it in stride and by the end of treatment, *"She was happy. And by a year after her diagnosis, we went camping. She was full of life."* Mother recalls that, *"The first summer after her first treatments with leukemia, I took her out there (to the ocean) and it was like there was nothing wrong, you know. She didn't have this battle previously and she was just a kid and that's what I loved about taking her there because she didn't have a disability. . . . And that's probably why she was so happy because she was a real swimmer. She loved to swim."*

When Mother and Father separated, Mother moved to the coast with Clare, where other family members were able to know the spirited little girl. Mother says, *"I'm so glad I (moved) because, as you know, I come from a big family. I had her 10th birthday and her dad and his mom and Brother and Clare and my family. We were all there. It sounded like a choir when we sang her birthday songs. She was just thrilled. She was jumping for joy that all of these people were there for her 10th birthday. And it was so special and also too, (sic) she got to know all her cousins and all her cousins got to love her. And it was only 14 months before she came back here for treatment. But they all got to know her and my sisters got to know her better and their children. It was a real special year for her. It was really good."* Clare enjoyed many hours with her cousins at the beach and became a *"water rat . . . she just loved the ocean, just happy with a bucket and a pail and water."* At the beach, *"It was like there was nothing wrong . . . . She was one of the kids because when you're mucking around with the kids on a boat on the water or whatever, you're just one of the kids.* Her *"magnetic personality"* attracted everyone who came in contact with her, adults and children alike. She was integrated into a regular school in a small community and the house was full of children after school and on weekends. "*And it looked promising and it was really going to be a place that she could grow into adulthood and I could look after her and that was my life. My life was with her until I was gone because I was going to look after her.*"

But then Clare became ill again. This time Clare was older and understood more of what was going on. *She would ask me, "Why? Why am I here?" And I would tell her, 'They are giving you medicine to get you better. So we can go and see our cousins.'"* Brother, who was quite young during her first treatments, worried about Clare. Mother says of that time, *"He was a very caring big brother. . . . And even though he was wanting (sic) to run off to play with his friends, he'd stop and say, 'Is she okay?' 'Yes. She's fine.' And then he'd run off."* But as they grew up and lived apart, the two went their separate ways. *"As he got older and she got more annoying (laughing) he wasn't as close to her. . . . And I didn't see it much (the second) time. . . .And with him and his sister, they were growing . . . apart. He was venturing off and she was sort of staying that little, that little girl."* But Brother was the donor for the transplant, *"My son was the perfect blood match for her and so it was her best chance in that respect . . . but it just didn't work. She would have reactions where she couldn't walk and her legs would swell up. She really ballooned up and it was really a difficult time right from the start. It was really difficult and she was that much older as well and, and she understood that she wasn't well and . . . . after three weeks (she) catapulted downhill and she passed away."*

The Family

When asked to tell who the members of her family are Mother includes her son, her ex-husband, her mother and father, and her two sisters. But for the last few years of Clare's life, Mother and Clare lived separately, a province away from Father and Brother. Defining this family, and establishing the norms that guided them, began when Mother and Father were married. "You just have to make sure that everything is there that you need and realize what it is that you need before you marry. And if you haven't been married before, how do you know that something's missing until it's missing? I thought we did. And then when we were married, I realized that we didn't. . . . I'm a walker and a hiker and I like to be outdoors and after we were married that stopped. We didn't really do anything much together." Mother moved to a different province, leaving behind her very supportive family, network of friends, and activities that were important to her.

"When I think back at it, a lot of our problems were starting before the birth of my son. Being two fairly dominant personalities, me being maybe, maybe not so dominant, but then once we were married, I kind of thought, "Oh well we're married now, there's no effort needed to put into the relationship." In retrospect, Mother realizes that she gave in to a lot of Father's hopes and dreams and gave up on her own. After three years of marriage she became pregnant. *"I remember feeling quite insecure being pregnant and that was three years after the marriage. A feeling that I had never felt before, feeling vulnerable because you really needed that person* now." When her son was born she became a stay-at-home mother changing the norm previously set by a couple. Mother adds, *"I had this incredible nurturing. . . .I couldn't imagine leaving him with anyone else. It was so strong. . .I just wanted to be with my baby and everything was great."* But as she explained above, two years later when Clare was born, her feelings towards being a mother changed. But the family settled into a new routine. She says, *"It worked and she had special needs so she demanded a lot of time, a lot of extra time, and everything took longer."* Mother's time, at home, was filled with taking care of her children and especially Clare. She describes Brother's independence, *"He was out on the street riding his bike with his friends and I was there with her."* Mother describes Father's role, *"He was a great dad. He spent a lot of time with his kids. He would have Clare sitting in her stroller and she was in her stroller a lot longer than any typical kid and my son would be scooting around on his bike."*

When, at three years old, Clare was diagnosed with leukemia, things changed for the family. For the first year Father was very angry and Mother felt blamed by him for Clare's illness. *"That was the turning point in my relationship with my husband because there was a lot of blame. And it was irrational blame. How could I be responsible for her leukemia? I felt there was anger for me. He was critical of me. He put me down. He put me down in front of other people. He put me down in front of family and his family. . .He would say, 'Your intellect, your appearance, your ability to be . . . . My mother can look after the kids better than you.' It's not rational and I know he knows that, but some of the things that he would say. . . .And when you are dealing with an illness and you got these things going on in your head and you got this on the side coming at you . . . . I remember at one point probably walking home from the hospital, we were completely separated emotionally from each other. . . .and just feeling screwed up. I don't know how else to express it. And that was sort of a turning point for me, but I had to get my daughter through her illness. And it's funny because once you say to yourself, 'I'm not going to* *take this. . . .You aren't going to talk to me like that. I wasn't responsible for this illness and. . .I'm not going to take this.' There was a role reversal. Now I was the one that was not putting up with anything and he, he became more quiet (sic) I guess."* By this time the couple had lost an emotional connection and was soon to lose a physical one as Mother moved to the spare room but remained in the home in order to provide some stability for Brother and Clare while Clare finished her cancer treatments.

During the time that Clare was being treated for leukemia, her paternal Grandmother, would come and spend long periods of time in the family's home and help by cooking meals, cleaning house, caring for Brother, and visiting the hospital, to give Mother a break. Mother valued this help and appreciates the deep bond it created between Grandmother and Clare. However, the separateness between her and Father was evident. *"When we had meetings with doctors, he would be speaking as if they were his children and I didn't have a part in that. (She) was my daughter and I would be sitting there. There was a lot of, 'me and my,' and speaking in singular, when we were a couple. And I think at that point I knew it wasn't going to work for me."*

Mother also received supported over the phone by her two sisters and parents. She also had the support of others in caring for Brother. *"He was really concerned. He was only in Grade 1 and we wanted to be at home a lot. Even his friend from school's mom would ask him over because they were wanting (sic) to help out. And I was worried about him . . . how he coped with that. So when he started school Grade 2 in the Fall, I had the school counselor talk to him to see how she felt he was doing coping and she felt that he was very typical and doing very well."*

Clare responded to treatment, *"She did really, really well . . . the initial 6 months was difficult, but after that she was very well. She was able to go back to school."* Once Clare was receiving outpatient treatments, things got somewhat better between Mother and Father, and Mother began to hope that her family would survive. At the end of Clare's treatment, *"Things were pretty good and I felt that at one point that the sickness kind of actually pulled us together. I remember feeling that we were closer together at some point . . . and as the years went by it was a distant memory. We felt that it was behind us."* The couple even took a trip to Hawaii and, when not experiencing the stress of a sick child, relaxed and enjoyed each other's company. But when they returned home and back into the family's routine, Mother realized how separate their lives had become.

They soon separated and Mother moved to her home province with Clare. *"When the break up finally happened, I was completely prepared. I wasn't shocked. I didn't go* *into withdrawal."* Brother remained living with Father. *"And so we all went out and Brother came back for the final year of Junior High and I saw him at Thanksgiving and Christmas. We saw each other a lot, but I didn't realize how hard it was going to be because he was only 13. . . . I didn't like that separation from my son. I don't know how long we would have actually lasted out there. . . . In theory, you think, 'Okay, well, we're going to see you and we're going to talk to you on the phone every day. . . .And we'll see you at Thanksgiving and we'll see you at Christmas. We'll see you at Spring Break and then we'll see you again at summer', which seems like a lot. But [it was] those 6 to 8 weeks in between that was…difficult. So, I don't know what would have happened [if Clare had not gotten sick again]. Making that decision for what seemed to be best for Clare and, no doubt, that part was."*

Life for Clare was very good. She came to know her aunts and cousins very well. But all too soon and with little warning, leukemia struck again. *"The blood work came back fine, but I knew there something was wrong and the doctors were trying to find out what was wrong with her and came up with the diagnosis of [rheumatic fever]… and I was quite shocked that she would need to be on antibiotics for about 10 years for this sickness. But before we could see the specialist, my pediatrician found some blast cells . . . and she started treatment. . . .She was having a lot of set backs, a lot of allergic reactions to chemotherapy."* Within a short time it was determined that a bone marrow transplant was needed. Mother recalls her reasons for returning to live closer to Father, *"I thought that it would be easier here so that she could be closer to her dad. But in retrospect it would have been easier for me [to stay where she was] because I had to move again. And then I would have had my family support. But I came back and didn't have a place to live and she and I had been getting an apartment a couple of months before having to go [for bone marrow transplant] so for me it would have been better if we had . . . .But not necessarily for her. No. Not necessarily for her."* She also believed it would be good for her relationship with Brother as well, *"and I think that was part of the reason too why I came back here, because Brother was here and I realized how much I missed him."* Mother felt it would also be best to bring Clare closer to her father because from the start, *"I felt when she was first diagnosed. . .in my heart, that it was going to be much more difficult than the first time. And when we were in the hospital I really felt that she was going downhill. But you keep your optimism, and keeping (sic) positive."* She stayed for a while in Father's basement suite, but when that became too stressful she found a place of her own. While Father was present at the hospital for some of her treatments, just as before, Mother took the primary role in helping Clare through it. Mother had the sense from the beginning of this second diagnosis that Clare was not going to survive; it appeared Clare did not feel this. *"I don't know where it came from initially, but when she was diagnosed I was grieving. I was grieving her death. . . .about 8 months before her actual death."*

Once again, Grandmother was a good support for the family. But Mother and Father experienced difficulty supporting each other in caring for Clare. Mother recalls one time when she took a brief break from her constant duties when Clare was out of the hospital for a short time and went to visit her parents, *"I went away too because I needed to have a break. Respite basically, so I could come back to it. And there was a lot of anger because I would phone him and he would be out with friends drinking wine. And I found out that she had to go back into the hospital the night before, and I couldn't understand how he could be out drinking, and her in the hospital, and he not there . . . because communication at that point was pretty very well broken down."* She adds, *"And meanwhile I had nowhere to live and was staying in the hospital with her at night. Just trying to keep things going . . .it was a struggle for me."*

When Mother and Clare had to travel to another city for the transplant, Mother's sisters took turns in coming to support them. *"My sister was, well one of my sisters was [there] with me for a week . . .before her death. And then, when she actually passed away, my other sister came as well. And my parents were [there] but they already had gone home. And they came back when she got the actual platelets from my son and then went home. And my aunt dropped off my mom and dad and picked up my sister, and so she was there at the actual time . . .(when Clare died)."*

When it was time for the transplant, Father and Brother arrived for the donation, but quickly left for a holiday in the States. For Mother it felt like Father, once again, "was running" and abandoning them. Brother *"had school and his dad was away quite a bit and I think on a trip for a few days right after the transplant. They had gone to the States for about five days. So Brother finished up school, so they didn't come back until a few days before her death. He was running away. . . . He hasn't verbalize (sic) that. But I'm surmising it …because throughout her sickness it seemed like he was in denial a lot of the time."*

When Clare died, Father was not there. Mother had to make the decision to have her cremated, after which she took her ashes and returned to Father's home to plan a memorial service. *"You're in shock, absolute shock. I think, actually, the whole year I've* *been in shock. . . .We had her cremated in [there]; I had to wait a day or two to pick up her ashes. [I] packed up the car, drove to [Father's home]. My family came from [out of town] and rented a house for a month. I stayed there a couple of weeks and had a little memorial service here."* Father took charge of the service and did things his way. Mother allowed this to happen because she planned to hold her own service in [her out of province home] with her family and friends, which she did later in that summer. *"We had her service three weeks after her death and then I packed up and drove to the airport and went back [home] for the summer."* Brother, who went to Switzerland immediately following Clare's death, did not attend the first memorial service, but came with his friends for the second service and spent the remainder of the summer with Mother. Her summer was filled with activity. *"Last summer I was doing home maintenance. My sister was saying, 'Are you nuts?' You know I was painting and landscaping and I seemed to have this energy and I think I've always had some energy . . . . .there was a surge of energy of getting things that needed to be done. And hiking, going up the mountain [with my son biking beside me.]"* But then it was time for school and Brother returned home.

Throughout the fall, Mother remained in shock. She found it difficult to begin her life without Clare and Brother, unsure what her life was to be. Her life quieted and she could not seem to settle into a routine without her children. She says, *"I think it caught up with me because I felt exhausted. When the phone would ring, I really didn't feel energized at all. I really didn't want to do much. There wasn't a lot of activity."* She missed Brother and decided to return to where he was living with Father in order to be closer to him, even though it meant another move. Mother says, *"It's better for me to be the one with the instability, as opposed to him going between people back and forth and not really knowing where he's at. I've made the choice to be the one unsettled and moving around."*

Throughout the fall and winter, she spent a lot of quiet time with Brother even though he remained living with Father. She says, *"We spent time having suppers and watching television and going for walks and things like that."* Brother seemed to be coping with Clare's death fairly well. Mother reports, *"He was very upset at first; then he seemed to be quite resilient. I don't know if he had maybe a little bit of angst because of the separation—between his dad and I; and then the death of his sister. I don't know if he's carrying anything about that. I ask him, 'Is everything okay?' [He replies] 'Yup. Yup.' [And then I ask] 'You hungry?' [He answers] 'Yup.'"* Mother laughs as she describes her attempts to connect with her teenage son. She realizes that their relationship is at a point where distance and separation is the norm, but she wants to stay connected so he is free to separate in his own way and at his own pace without worrying about her or Father as he now seems to be doing.

Brother seldom speaks of Clare. *"I don't think I've ever seen him cry and talk about her too much. I'll talk about her and say, "Oh you remember that time?" He didn't seem to show a lot of grief. . . . He actually hasn't said anything like "Do you remember that time?" Not that I recall. I think he's a little nervous about bringing her up, because I know with his father you can't mention her name because his dad starts to cry. Whereas, you know I'm not at the point where I can talk about her and smile. But whereas his dad, he really is having a difficult time with that."* She further reports, *" [Father's] still having a really hard time . . .he can't seem to talk about her without breaking down and. . .I've been saying he should talk to somebody. 'It's not going to make you less of a man to speak to somebody.' Maybe it's going to bring some other stuff up. . . .He's really having a hard time. We had a tape made for her Memorial Service with all her photographs, hundreds of them. . . .I haven't been able to watch it because I know what it's going to stir up. I will watch it again; but I feel I don't need to watch it. I have her photographs around my house. . .but he really feels the need to watch it a lot. . . and he'll be red-faced for hours afterwards. . . .it's his way, I guess, of dealing with it. I think it's hard on Brother, and I think that's maybe part of the reason he doesn't bring it up. He feels, 'Well, if I bring her up then my dad's going to be. . .upset and cry.' And so he kinda keeps quiet about it. And I know he has mentioned to me once, that, 'You seem to be doing okay, Mom, but I don't know if Dad should talk to somebody.' So, maybe that's why he doesn't, because he doesn't want him to be crying. Because it's over a year now, and I'm not saying that it should be any less. Actually, though, for myself, (sic) it seems to be even harder because it's set in. . .the reality, after the year. But . . .those deep crying jags, for me, are becoming further and further apart."*

She realizes now during the time she and Clare lived away from Brother that they had not had time to restructure their family after divorce. *"The last four years have been an intense four years. That's why I'm ready for a home. I've moved seven times in two years. . .and I think I'm ready to settle down, like I think I need to nest or get my home together."* As well, she now knows that even if Clare had lived, this move would likely have been needed in order for them to find a satisfying way to be a family. Her desire to be closer to her son and restructure her family following Clare's death is required so that

Brother can prepare to launch into his own life. *"We've decided that this is the last; I'm staying here until June. And then we're going, well I'm going back and he's going to finish grade 12 here and hopefully come out after that. So, he'll spend the summer with me. This next summer and we'll see each other over holidays. And he says he wants to be out there, but, who knows? I would like him to. . .do university here. But we'll see what happens. . . .The separation had been . . . well, we're going to be separated four years. . . in January. . . .That's a long time now. I suppose I have sort of a different situation where my son's here. He grew up here. This is his home, but it's not really my home any more. I've got pulls on the other side. My parents are getting older, and, I want to be out there. Whether that's--a pipe dream or not, I don't know. I haven't been out there long enough for so long that--may not work either. So, after this year, my family is going to be re-structured, hopefully with my son. And that's going to be the base for he and I out there. And [I]hope that we can make it work."*

Mother telephones her sisters frequently to talk about Clare and *"I have a good friend, we walk together. . . .I'll talk to her."* She adds, *"Clare's birthday was last week, so two of my sisters phoned to see how I was doing, and see how I was making out."* She has had to learn new ways to cope, *"I felt keeping busy was the way to cope, but then I realized that might not be the best way to handle grief. I needed to slow down."*

As the anniversary of Clare's death approached, she was unable to decide what she should do to mark the day. She thought, *"I would like to book a trip to the seaside . . . with those waves coming in. That's where she was so happy."* But instead she decided to get a tattoo for two reasons: one as a permanent way to carry her daughter with her and another as a way to share the pain of the needles Clare so feared in life. Part of the tattoo, which remains to be finished, will be Clare's nickname in Gallic - a special personal reminder.

Clare's ashes remain in Father's closet, and although Mother feels ready to scatter them over the ocean that Clare so loved, Father is not ready to do so. Instead, he suggests, *'Well, you take half and I'll take half,'* a suggestion Mother could never take, *"You know as if we would do something like that! . . . I would like to take her ashes out to B.C. and spread them on the seaside. . . .I'm thinking he would like to have her in an urn on the mantelpiece, which is fine if he feels that strongly about that. . . .I'm not going to separate her ashes, even though they would get separated, obviously, when you spread them."* She is prepared to let Father make the decision regarding Clare's ashes stating, *"I'm a realistic.(sic) They are just her ashes. It's not her you know. They are just* *ashes and that's all.* Recently, she thought that burying her ashes, with her maternal grandmother, when she dies, might be a good compromise that would honour the special relationship that Clare had with her grandmother.

Today, Mother still feels that she is in transition with little vision of the future, *"I don't really see too much. I want to feel at peace. I'd like to . . . say it's peaceful. And it's a year now. And I find that really hard to say it's been a year. But I've said that in the past as well, 'Boy [this year] has gone by fast!' But it just seems like just yesterday. And now it's a year. And I think I used to hear that after a year that you would feel better—and I think I do, in a sense. I don't have those gut-wrenching cries in the pillow that I used to have."*

Despite the many hardships that Mother has had in restructuring family, she remains hopeful that one day she will feel that sense of family again. *"I haven't really had a home. . . .Over the last few years, I haven't been settled. . . .So if I think of family, it would be being settled in my own place, with my son. Or knowing that my son would be on his way at some point soon. But I wouldn't say that [is] now."* She has learned *"that life is a series of grief and mourning. But there's a positive, somehow. I don't know how, there's this. . .strength, growth, there's something. . .that it gives you, a certain power or. . .something positive. That part of me just has to grab it or that sounds kooky. And what form it will take, I don't know. It also makes a lot of things not important, that once were important. Things. . .that people think, or one time I thought, were important before, are getting more. I think that's worth searching for that peace. Right? That peace will be worth achieving."*

"*Families carry their grief along*"
When Individual Grief is not Given Voice:
The Story of the Stewart Family

The second family story, again, speaks of the lack of "family work." Only Father Stewart told the story of Baby Lawrence who died 30 years ago as a result of Sudden Infant Death Syndrome (SIDS). After struggling as a family for 12 years after Baby Lawrence's death, Mother and Father divorced. In the interview Father revealed that even his "individual work" was delayed due to his drinking. Father is now aware that this blocked the pain he felt in his bereavement; he tried to carry on life as it had been before Baby Lawrence had died. As he spoke in the interview, his story revealed how his drinking caused him to be absent from his family emotionally, as well as at times physically, as he found more opportunities to drink with friends. His absences from his family appeared to block communication between the couple.

Father Stewart was the only parent who did not have memorabilia or photos to share with me. He felt he could not ask his surviving children to take part in the interview since they have never spoken of Baby Lawrence. Further, he reported that he and his ex-wife are no longer on speaking terms. It is his perception that his marriage was a good one before the death of Baby Lawrence and the start of his alcohol abuse, hence the reason for his inclusion as a negative case. His story contrasts with the other findings in this story and those reported in the literature that only poor marriages end when a child dies. However, it is important to remember that had Mother been interviewed, she may not have agreed with his assessment of their marriage previous to the death of Baby Lawrence. It maybe that Mother and the surviving children did "family work" of which Father was not a part or aware. However, his story illustrates how when one member's grief and mourning is blocked, it can not be shared with other family members and limits their shared work.

Telling the Story: The Spirit of Baby Lawrence

Father sadly reveals that his family has not created a spirit of Baby Lawrence. Although the family had photos of Baby Lawrence, "*Just a couple of googly pictures. . .when he'd be waking up. . .pictures of Mother rocking him or me rocking him*" up in their house, they never talked of him. When I shared my model of family bereavement with Father, he recalled that his own mother and uncle always spoke of the spirit of their brother, who had died as a baby, and how his own family has not created a spirit of baby Lawrence. Father says, *"And when you're talking about family there, where, what's the. . .the loss of Baby Lawrence. . . .In my mother's family, and my uncle who's still alive, and I still stay in touch with; my mother died 4 years ago now, in March. So anyway, on their tree, there's Uncle, Uncle M and then my mom. And Uncle M died at about 8 months. He was very asthmatic. But they always talk about Uncle M. . . .families carry their grief along. . . .And my mother and Uncle always talk about Uncle M. . .into their 80's. . . .But I don't hear my children talk about Baby Lawrence. . . .But there was Uncle M. There, on my tree, there's Uncle M."*

The Family

The Stewart's were a young family with three children, including Brother aged 3 years and sister aged two years, when Baby Lawrence died at 3 months of age, from SIDS. Father recalls that, *"We just, as a family, were getting settled with three children, in the house. The house was small, but not that small--not huge. And life was good. I was making good money. I had a great job, good friends, good standing in the community. Life was busy. We had opportunities. We were living in a small town in B.C. . . .We had a third child. . . .We were active in the community; active in the Church. . . .Lots of nieces and nephews in our lives, both grandparents; it was just busy. . . .We were busy traveling. . . .I was successful."*

He remembers the night vividly: *"I was at a Kinsman meeting and Mother was out, We had a babysitter - a very reliable baby sitter that had babysat our other two children. Baby Lawrence was lying on our bed, our big king-size bed, queen-size bed I should say, with pillows around him. . . .And Mother came home and found him cold. . . .Our neighbor was a Mountie; she was a friend of the family."*

But. immediately on learning of Baby Lawrence's death, he remembers: *"I was just so raw . . .just so much full of pain and hurt. . . .I never had a chance to grieve. You know, it just seemed like the world should stop, with how much pain we got. . . .I was shaking. When the Emergency [Services] came, the police had to come, and she came to the house and he came and got me. . . .And I didn't know what the hell had happened. It was about 10:30. [Emergency Services were] already there; they had already left. They had taken Baby Lawrence. . . .Mother was vibrating in the chair. . . .And she didn't know what to say because they'd already taken Baby Lawrence to the hospital. . . .We didn't know what caused it. Just that they couldn't revive him. We never got a chance to see him again . . .until the funeral."*

The next day, Father remembers that there were so many things to do: *"You go to the City Hall and you get a burial plot. You go to the Church, and you go to the Funeral [Home]. We had different Churches. . . .A name in the paper, side by side. . . .And everybody that came to our house later on, by ten o'clock the next morning the whole neighborhood knew that . . .we had food for 2 weeks. . . .And we had to wait for my mother to come from [another city] and for my in-laws (L and D) to come from [another city] and everybody flew in. . . .The house was busy. . . .You have all these people around, and yet you feel so alone inside."*

He coped with this tragedy as he had so many years before when he was only six years old and his father died. He explains it this way, "*My father died when I was 6. . . . And 2 days after, like, I was the oldest of 4. . . .You go out and be self-sufficient and grab pop bottles, what you need to grab; make your own money. You're working; you're independent; you don't ask for help. . . .You get through the grades. You cheat. (laughs) You do what you can. You got two choices. You want to be on the good side or the bad side of the fence? . . .Can I be over here for a while, or do you want to be over here? Because that's boring. . . .That's how it works. . . . So, whatever worked, worked. You survived.*"

Many years later he learned that he had been given strong messages from family members on how to behave. He adds, "*I'd seen [a program] on T.V. on PBS. [The speaker] had lost his father as a child. . . .And he said something like, 'When my father died, I can remember all my uncles around, or the ones that were left, saying, "You're the man of the house. You look after your mom". . . And, and that's strong. You gotta be strong for your sisters. . . .And I've always tried to be that person. . . .And, and it's unreasonable. . . .You build old survival skills on strong survival skills. . . .Or what I've heard and learned from. And they're old survival skills from when you're a child. . . .And whatever worked back then might have worked for a little bit, but they don't work today.*"

Now, 30 years later, Father is unable to remember how the family survived from those busy days through the next few years. He recalls: *"Life was good before. . . .It came to a head. . . .It was traumatic for me, anyway. I don't know how it was for Mother."*

But he remembers standing at his young son's grave. He recalls, "I*'d known for a long time, well not a long time . . . .that I was probably an alcoholic and how alcohol got me in trouble. But I promised on his graveside I'd never drink again. . . .I couldn't keep that promise. [I] couldn't do it for 30 days. That's always been troubling my mind. That's part of my story.*"

And he now realizes that his drinking blocked his feelings of grief, "*Oh, it shuts you right down. When I would drink, I wouldn't feel anything.*" However, drinking was not new behaviour. He admits: *"Before I'd even met her [Mother] in '71, I'd already had many blackouts. I'd already had problems. . . .I know it caused me problems with relationships. It caused me problems with the family, with police, [and] with my employers."*

But Mother did not fully realize the problem at that time, as Father tried hard to handle it. He describes it this way, *"Well, I tried to control it all through that. I'd have the* *blackouts and see that. Now that I've seen my life that, "You're married. Or did you take a hostage?" You know, at least you're trying to be responsible and you're trying to do the things because you love the woman. . . .You want the responsibility. You want all this. . . .And all of a sudden, things change, and what do you do? You become more social; you drink twice a week. You do things more, and all of a sudden more alcohol was consumed. . . .And that happened after; it had already started to happen."*

He adds, that if she was asked today whether she felt, before Baby Lawrence died, that Father had a problem she would say: *"Oh, probably, 'No.' [Before Baby Lawrence died] . . .I renovated the basement and put a sewing room in there and thought she'd like it. And that allowed me to be at Kinsman [meetings], you know, consciously or unconsciously. . . .I think it was these, or results of self-centeredness, that takes you . . . for more and more and more . . .not understanding it at the time. But today I see it. . . . But [at the time] she wouldn't have said that. . . .She would have said, "He did these things because I wanted it and he was willing to give me what I wanted. . . .I did it willingly."*

Father recalls the early years of his marriage this way, "*Ah, it was exciting. We were partners. . . .You know we did things together. We took holidays together. . . .We took holidays with the family. . . .We were complementary. . . .Our communication was fairly, really good . . . very trusting. It was open. . . .And she supported me in my career. . . . [And] she liked to work part-time, or to get out. . . .And so we had an arrangement for, even when Brother, even when our first son was born, she worked . . .part-time. . . .I maybe put her on a pedestal. But today I see that differently . . .where we did things that allowed me to screw up later on."*

One such incident was a decision he made shortly after Baby Lawrence's birth: *"Maybe Lawrence was planned by my wife, but not by me. . . . And I guess my opinions and my goals and objectives at the time; I'd come from a labor intense job to the insurance industry and I was fairly, real successful at it. . . .I had these goals and I didn't know if I needed more busyness in my life. . . . Although, I loved being a father and I loved being an uncle. I loved that part of my life. . . .I loved my community, my wife. And so, after the baby was born, about 6 weeks after, I went and had a vasectomy because I was, I didn't want any more children."*

He adds, *"I agreed to it [vasectomy]. . . .She agreed, but she wasn't going to go for a tube ligation. . . . And I said I would do it. . . .But I don't really know if that came from her mind. . . .Or if I didn't talk; or I made that decision for me. . . .It was good for* *me, for sure. . . .And I guess that's, one of the problems in our marriage, was that I did a lot of me things. . . .Or I talked her into it."*

He now wonders how this event affected him and his marriage after the death of Baby Lawrence. He says: *"So it was me doing that and it was the loss of Baby Lawrence to fulfill my having three children, and me not being able to have any more. . . .I don't know what she thought. We never talked about it."*

As the months passed, Father tried to continue to remain busy and involved in his life. He recalls that even in that first year the family maintained their routine: *"I didn't drink for 30 days. I curtailed my drinking quite a bit. I got really focused on my business. . . .I set some goals and objectives to [move] closer to her family and my family. . . .I got promoted. . . .My sister stayed with us. . .and her child. So, that was good and bad because she and Mother didn't get along that well. . . .So it would be a bit of a comfort to have her around the home. I appreciated her being here. . . .I don't know if Mother did. But her family and her two brothers had their own life. . . .But it's the way I got, or tried to get my life going again, was to get re-focused on my business and my goals and my objectives and my dreams. And I had written these all out. . . .We'd written them out. I used to set goals every December and try and plan things all out for the year. . . .We did that that year as well. And we had a big convention, I think, that year, in 77. It was in Quebec City, so we took a big holiday there."*

But the young couple would talk little of Baby Lawrence or share their pain: *"I never cried. . . .She might have. Actually, she did. . . .[But] holding her and comforting her, I can't remember doing that. . . .But I think I cried in the basement, by myself. . . .She'd never see it [my pain]. She'd never see it."*

The one thing Mother and Father did was to try to understand why Baby Lawrence had died: *"We did some research on SIDS. . . .We found it was frequent, more predominant in boys than girls. . . .And we talked about things like that and realized it was not our fault. . . .And Dr. D. helped to relieve our. . .frustration. . . .So we found some commonality there. But we didn't know anybody who had experienced that. . . I did a lot of reading at that time. I did a lot of it. And Mother, with her librarian background, she'd get things. But there wasn't much on it. . . .You know, at that time, back in '76. . . . They were just starting to study it. And it's interesting, the things that come out when you read a lot, or you read quite a bit. And you get pictures of what someone said, "Oh, I can identify with that. I can identify with that. [But Father adds:] You try and hold all the eggs* *together . . .you don't show it. . . .You don't ask for help. . . .[You hold it in]. . . .All the time. . . .When you have no support, you don't understand it."*

As time passed Father realized that his drinking was becoming problematic: *"I went to the AA meeting at the United Church, and I went back to my Church. . . .I drive up in my country square. I thought, "Shit. I can't park here. Everybody will know I'm an alcoholic on Tuesday nights. I don't need this." I didn't even start it. . . .I went looking for help, but I didn't want anyone to know. . . .I knew I needed support. I'm in business and I've got . . . community members. . . .He said, "You can do it on your own. Any man can.". . . .I went, "Oh, yeah." You know, he's sober for 8 years and he hasn't had a drink. . . .I wasn't worried. . . .So when you hear those that, when you're an alcoholic and you're sick, anything that will rationalize the way you're going, you'll hang on to it. . . .You don't go for help."*

But Father now realizes that he was not willing to openly grieve. At that time, he searched for answers but realizes now that he wanted an easy way out of his pain. He recalls the trusted friend who gave him a message: *"A poster that [friend] gave us, was, I still have it. It's a waterfall in the forest where life's meaning or "love's meaning is life's secret". . . .I asked him [friend], we were asking him, "What does that mean?" He said, "Well, it's a journey. In the journey, you'll find out.". . .It pissed me off. Just give me the short answer."*

He also made other attempts to grieve including: *"You know I had, I made these big pillows for Christmas, for the kids, for each one of us to lay on, on the floor. . .I stuffed them and made these to play with on the floor. . .these huge pillows. . . .And I went down there and I prayed to God. And they were different prayers then than they are today. In my understanding, it was. I wasn't praying to be a comfort to Mother. I wasn't praying to be a comfort to my fellow man. I was more praying, "Please help me," not realizing that, then, as I feel today, that you get your own comfort by being comforting. . . .It's a fine line, you know. You gotta give it away before you get it. . . .And I didn't understand that."*

He was unwilling to share his pain with his family or seek ways together with them to grieve and mourn as a family. In an attempt to find the quick answer, the family moved. Father learned that the pain just followed: *"And then we had. . .the crash came. We went bankrupt. Her brother went and got divorced and moved in with us and just things. Chaos just seemed to build."*

At first the family managed, trying to ignore their loss. Father remembers: *"We'd golf. We skied together. We played ball. . . .When they weren't old enough to play ball when we came here, I went to all the hockey games. I coached. . . .I did Tee Ball. I took the kids to piano. . . . I took the kids to bowling. They had bowling functions. As a family, we did things together. . . .We went camping together. We took family holidays to Disneyland and Disney World. . . .On the weekends, we did things together and our friends would come over, or we'd be playing bridge someplace, or somebody would be coming over to our place or we'd go over. . . .The way I see it now, if I didn't have my Scotch, we'd go someplace else. (laughs) Wherever they drank was good for me."*

Even though the couple never fought, *"Not before we were married . . .and not. . . early in the marriage. [It was] not until we moved."* It was 2 years after Baby Lawrence died that the couple began to experience difficulties. By this time Father recalls that, *"There was not all the physical attraction, all the emotional attraction; there was no good feeling, no comfort in bed, no comfort in coming home and getting a hug, no comfort in giving her a hug. There was no good feeling that way. . .probably shortly after we moved."*

There was no open discussion of grief or sharing of memories: *"I think Mother might have a couple, a blue sweater and a bonnet, for sure, and a rattle and things like that. The crib we had when we moved here, and we gave it away, but it was Sister's crib. . . . He never had a crib. . . .He slept on a bassinette; he wasn't old enough to sleep in a bed. . .I don't [remember what happened to that]. . . .It didn't stay around long. I'm sure Mother gave it away. . . .I don't remember. . . .We sort of put it to bed."*

Father recalls that when Brother and Sister asked about Baby Lawrence, the couple would just answer: *"He's gone, the baby, Jesus has him in his arms. . . .And he's in Heaven."* The family never visited the cemetery together. Father says: "N*ot as a family; I'd gone . . .probably, about 6 months later. I think I went once by myself before we moved. . . .I don't know if Mother has gone."* The children learned quickly to forget their brother. As things continued to deteriorate, Father now understands: *"So you put all those eggs in a basket and you wonder why you feel like general manager of the world, why you can't get it together. . . .And you get in a rut. Basically what you're doing is running, instead of staying focused on the problem and fixing that first. Nothing's ever getting fixed along the way. . . .You're always chasing the chaos. . . .And you don't talk about that chaos; you don't see it."*

Eventually, it was his mother-in-law who confronted him about his drinking. He recalls that loving act and the action he took and those he refused to take: *"But Mother took a trip, and I remember going to her parents' place . . .her mom, she was a night owl, and I was up drinking. And she said, "Father, come here. . . .We've got a problem. We love you. You need help." I said, "I'll get it under control." I sat on the side of her big bed. And I told my minister that I had a drinking problem. . . .So I went and, and I poured my heart out to him. I told him I couldn't get stopped. Every day I was buying a 26 and I'd say this was the last day. And we'd gone through a bankruptcy and we'd cleared that up and I was back in business. And paid off everything. We still managed to keep our house, keep the house . . .and losing that and losing it. So anyway, I went bankrupt. . . . And once that happened, I just couldn't hold it together with the drinking any more. I'd get up at 11 in the morning and I'd start drinking. I'd come home at 11 in the night and get my bottle from underneath the couch or wherever I had it hidden. Mother was marking it. So I went and talked to Father K. He said, "Oh, we'll handle it together, just a day at a time." I said, "Oh, that's good." So, two days later, all my hiding spots are gone. He went and told everything to Mother that I had told him. But now, she knew how bad my drinking problem was. . . .[She had been saying nothing, but] she made two comments that did strike home and hurt; that hit me right in the heart. One was: I came back with the kids from piano lessons. And I'd had two drinks. She smelled it on my breath. She said, "You're drinking and driving with the kids." And it just. . . .And I knew exactly that that was more hurtful than anything I could do to her. . . .And we never had an argument, you know, in the 12 years we were married. I never had to raise my voice. The tears would come to her eyes, or her body language; she'd walk to the bedroom alone or I'd stay in the living room alone, or whatever. . . .So, we just, just like that. So, anyways, after telling Father K. that and she finding out how bad my drinking was and we'd just got discharged from bankruptcy. And I couldn't get to work and work effectively . . .I think I'd re-established my credit. I got my Master Card back. And the bill came for about $700 and that was liquor. . . .She opened it and she found it. She was devastated. And that was the last straw. . . .She said, 'I'm leaving.' And I never asked her to stay."*

But this further loss of his family proved to be the breaking point for Father. He says: *"And I made two calls and I cried. I called my mother. I called my good friend. And I went to work. I let her take everything that she wanted. I said, "When you're ready to go, just go." And the first of May she was gone. . . .In the middle of June I went to my boss H. and I said, "I've got a drinking problem. My wife is gone. I've gone through the* *bankruptcy. I don't know what to do." We walked down to AADAC together. . . .[Later] I asked her if she wanted to try again. She said, "No. I'm not falling for it." There's always a breaking point for everybody. . . .At that time, you know, I used to think she was weak in some ways. But now I know she has great strength. . . .She did the right thing and I'm grateful that she did. . . .I've been sober for 22 years. . . .You get messages in your life in strange ways. (laughs)"*

Now Father can see that his fear overwhelmed him: "*Fear of letting somebody in, fear of being, of showing some weakness, fear of whatever, fear of trying to love again, or fear of taking a chance."* And he regrets what occurred for his family. He adds: *"It takes great courage. And then, the two people that are going through the grief in the family, or the children too. . . .You don't know, but if you're not giving . . .and sometimes, if you're not giving it back, you're not even feeling [what] your spouse is giving you. . . .She's there every night and she's going to work and she's feeling it and she's looking after the children. . . .And when you're in that place you don't see it."*

It is only recently that Father has allowed himself to grieve and mourn the loss of his son. He says: *"And I feel that mourning. I've cried more in the last 5 years than I cried in my whole life before that. . . .I've driven; last year driving [another province]. I went back last summer and visited; I just broke down on the way. I broke down on the way back. . . .Two years ago, driving to [another city] at Christmas time, I just broke down. . . . Coming back, I just broke down in the car. . . .Just during the drive, just pulled over to the side of the road and cried."*

He regrets the effect his drinking has had on his family but believes: *(long pause) "I've thought about that from time to time. I think the way I was geared, I would have found a way to push her out of my life. . . .the way I see it today anyhow. Hindsight is always 20/20 but. . . .(pause) My experience in relationships has been that somehow, women have left. . . .And that's just the way it is. I'm just; I'm a lucky guy to have had her love for so long. It was good and I had part in some good times. A good part of it, with all of them. Painful for Mother and the most painful, for sure, was for the children. And I don't know if it was my fear about making a commitment or whatever."*

When he viewed my visual representation of family bereavement, he shared his thoughts on the importance of loving acts: *"I think this is the most important part. . . .If you're not doing the loving acts, you don't feel it and you're not getting it. . . .And it's gotta be unconditional. . . .And that's the only way you can feel it; and that's the only way I can get over it. "*

"*Remembering – is acceptable*"

Individual Mourning and Kindness Acts of Others:

The Story of the Fraser Family

The story of the Fraser family is told by Mother alone. It has been five years since Neil suddenly died from a complication of his chronic illness. In that time Mother and Father have divorced and Brother remains living with another as he prepares to launch from home into a life of his own. The family norms, well established by the time if Neil's death, have meant that family members are alone in their grief and mourning; there has been no family work. Mother asked Father to participate in the interview but he refused. As Mother proceeded in telling her story, it became obvious to me that the family's communication patterns would not have supported an open expression of their grief. Brother was not asked to take part in this study because he was off in a faraway province studying and not expected home during this time. Following my first interview with Mother, I did not asked for permission to contact Brother by phone since she so strongly indicated that Brother did not speak of Neil nor his death. Mother chose to do the interview alone, not including her mother or sister. With the telling of her story, it appeared that grief and mourning in the Fraser family is a solitary experience; one where Mother struggles to mourn her loss. Fortunately, Mother's strong faith has given her outlets for support. It was Neil's friends, who have learned through their education the cultural rituals to lend support and thereby became Mother's "family of choice' during bereavement. It is in this small group that Mother has been able to tell and hear the stories of Neil, allowing her to remember her beloved son.

Telling the Story: The Spirit of Neil

Telling Neil's story is limited because, in the Fraser family, only Mother speaks openly of her quiet gentle son. Father and Brother refused to speak of Neil, perhaps because five years after his death it is still just too painful for them. Neil worked hard at creating closeness with his Father and Brother. Mother said, *"He would insist [on trying to get close to Father]. He would come up to his dad; he would hug his dad. He would sit on his lap. He would say, 'Come and play ball with me.' 'No.' 'No! Come and play ball with me.' And he would not relent or give up until he went."*

Mother describes Neil as, *"Good-looking. Kinda tall and gangly. Very, very gentle, very, very soft-spoken. I learned to speak softly from him . . . because he would* *get very upset if you raised your voice . . .Very gentle. Very smart. Just a wonderful student. He loved athletics, and had a lot of friends. Really well-liked and well-respected by his classmates."*

Most of the time it appeared that Brother and Neil were not close. *"They didn't fight. They, both boys were peacemakers. . .which are (sic) very interesting because people say boys fight and girls don't. And others would say, 'Well, don't they fight?' And I'm going, 'No. No. They find some way around that.' I wouldn't say they were particularly close. I mean Neil was asked by one of his friends about his brother and he said he didn't have anything to do with Brother. (laughs) But, if Neil needed anything with the computer, like Brother is very good with the computer. And when he was stuck, he would go see Brother and Brother would help him."* However, their nightly routine made Mother question if the apparent distance between them was real. *"They [had] this little bedtime routine and so I think they were closer than they let on. I'd be in bed first. Right? I'd be exhausted. I don't know whether Father was in on all of this bedtime routine, anyway I'd be in bed. And then Neil would come up to bed. And he'd always come in and, and we'd have a little snuggle and that sort of thing. I'd give him a little backrub. We'd have a little chat and a hug. So then, he'd go to his room. Then Brother would come up (laughs . . .and [he] would come in and say goodnight to me and give me a hug. And then he'd go to Neil's room and I don't know what they did, but I think they chatted and hugged because quite often and you'd hear Neil say, 'Don't go yet.'"*

But Mother cherishes her memories and the stories she receives from his school friends. When Neil's friends gathered at his grave site with her to remember a boy who contributed such a kindness to their world, Mother is filled with joy. She says, *"This little boy here [points to him in one of the pictures she is showing the interviewer], he wasn't a particularly close friend of Neil's. And in here[special memory book] he wrote about how he didn't know Neil, but in grade 6 they went on a school camping trip. And he was in Neil's cabin, so he got to learn more and got to appreciate what Neil was like. And, it's only the last two years that he's come to the Memorial Service."* As well, Neil's friends still phone Mother and visit, bringing their stories of Neil. They remember him as a quiet, gentle, and caring boy. They tell mother how much they still miss him. *"I had a visitation from two of the girls. A visitation to see me: on the anniversary. . . .And so they asked me to get out the book. And they talked about Neil and talked about how they remembered him. And, one of the girls was so cute. She said, 'Now, Neil had this really cute pencil case,' she said. 'Do you still have it?' I said, 'Yes.' 'Well, could I see it?' I* *thought, 'Oh, my gosh, where is it? We've moved. Do I know where it is?'. . .And, so I found it. And I gave it to her. I thought that was so sweet."* These are the opportunities that Mother has to talk of her son and to remember him.

The Family

The story of the Fraser family and the absence of mourning in the death of Neil is predicted by the family norms that had been established many years before. Mother described her marriage this way, *"Very much laissez-faire is the word that comes to mind. He didn't make many demands on me. . . .I placed them on myself. . . . I could pretty much do whatever I wanted to do. But the trade-off was he could do whatever he wanted to do."*

This was a family where Mother and Father led separate lives. While father was putting in long hours trying to establish a family business, Mother was working full-time to support the business and also run the household and provide care to Neil and Brother. She was exhausted by all this work and relied on her mother to provide support and aid her in running the household. Mother added, *"I did it all [laughs] . . . .Well Father worked. . . .He left the house to go to work . . . .My mother had spent a fair amount of time at our home. She'd be at our home several days during the week. She didn't drive, so she would come, spend a couple of days, then she'd go. . . .She'd be a real big help in getting the boys off to school and being there when they got home . . .and getting supper started. So the boys would go off to school and then, when I got home we'd have supper; I'd finish making supper and we'd eat supper. And then the boys were involved in dancing. There'd be two nights a week where I'd drive them to their dance class. . . . And then, if it was springtime. . .that means soccer two nights a week. I think, in that last year, Father was more involved in taking Neil to his soccer games. But before that, I'd try to re-arrange everything so I could drive, [Father would usually be home for supper]; and then he'd be gone in the evening [as well as on weekends]."* It appeared that there was little time for this couple to talk about anything, and what conversation they had was limited to the practicalities of life. *"He was pretty, I wouldn't say disengaged, but he was all wrapped up in his work"* Even when Mother felt that she and Father had made a decision on something, he would often go off and do something completely different. The family did very few things together; *"He [Father] just wasn't ready to socialize,"* Mother tells of her husband. But he would go to some activities for the boys, *"There would be* *soccer tournaments and things, or dance competitions. . . . So Father would go to both."* They were not an affectionate family rarely giving hugs or kisses.

Mother's family of origin consisted of her mother [who was very seriously ill when Neil became ill] and her sister who had a long term chronic illness that kept her housebound. Mother had long felt like an outsider in Father's family. She reports, *"They just had a real hard time accepting outsiders in."* Father insisted that all family holidays needed to be spent in the country with his family, precluding the family from setting traditions of their own. Mother recalls, *"And for his family, it was always very important that everybody be there at Christmas Eve . . . you stay Christmas Eve and you stay Christmas Day. And then we'd usually go home Boxing Day. And that was, they kind of expected everybody to come. And so we never really developed our own traditions because we always went there."* Mother and Father were from different cultural backgrounds, making it somewhat easier for them to be with his family on these holidays, and with her side on their holidays, which were celebrated on different days. Mother adds, *"So, we rationalized that. . . .And then, for Easter, it would be the same thing. We'd go; and that was just the way we did it. . . .I think we [discussed it] one or two times before the kids arrived. But we never, once we had children; we just carried on."* However, Mother insisted that the boys attend a school that immersed them in their culture and Father did not object, an important experience once Neil died.

When Neil became sick at 4 years old with idiopathic thrombocytopenic purpura (ITP), and later required a splenectomy, it was Mother who took him to appointments and watched over him, protecting him from infection, and seeking immediate medical help at the first sign of this life-threatening event. *"He would need regular blood work, and depending on what his blood work said, then we'd rush off to the hospital. Work was very difficult because I never quite [knew] when I'd have to leave and go into the hospital with him. And it seemed to have been my responsibility to do that. . . .Then I took a year off work because it was just chaos . . . and then he was old enough to have a splenectomy. So at the age of 6, he had a splenectomy. And he was followed up by Dr. A, but it didn't cure him, but the spleen wasn't there to destroy his platelets. So, from the age of 6 to the age of 12, he really was quite healthy. We were alerted that if he ever ran a fever, to take him in."*

As the years went on Mother, *"just assumed the responsibility for that, when to take him in and . . . it was really up to me to monitor that and to make sure he took his medication."* She became exhausted and depressed as Father continued to be absent physically and emotionally, and denying that his son could be at risk of death. Mother says, *"After a while, you get a bit complacent. I knew the risk of bacterial infection. But you don't dwell on it. . . .And every time I worried about something, Dr. A would just give me heck for being a worrier, but we realized later, in discussions, that Father really didn't have an appreciation of what the risks were."* Paternal Grandmother supported Father in those beliefs, stating, *"Well, he's going to get stronger."* But Mother adds, *"And well, strong has nothing to do with it. [laughs]. . . .And then I didn't realize that Father had the same attitude."* But Neil did recognize the risks infection posed to his life, *"[Neil] would have seen himself as well . . .He was quite attuned to how he was feeling. And there would be times when he'd say, 'Mom, I'm not feeling well. I don't think I should go to school.' And so, we'd keep him home and . . .his life kinda depended on what those blood tests showed. . . . So, he kind of knew that."*

Mother tells how Father did not attend to the signs immediately as Neil became ill. She reports the events that lead up to Neil's death: *"Just a few days before he died, I had to go to Ottawa for a business trip. Father was at home with them. I phoned every night, and Neil just had a bit of a cold, nothing really that was untoward. And he maintained his activities and so on. But I guess on Saturday night, when they went to bed, Father noticed Neil went to the bathroom a lot. He never went to the bathroom. And he got up to take a look at him and he could see he wasn't well, and decided to take him in. And by the time he got to the hospital, he went into septic shock. And [he was] admitted right away and put on life support and that. . . .I was still in Ottawa, and couldn't get back until that evening. . . .I had a pretty good idea [what this meant]. I mean Father was probably always more hopeful in those three days, that everything would turn out fine, than I. . . . I don't think I let myself get that hopeful. I think I was already aware that he wouldn't make it. . . . Meanwhile they put him on ECMO and when I got there, I found out he was on ECMO and there was still quite a bit of hope that his heart would be stronger and he would come off. So the plan was to take him off ECMO on Thursday morning. But the nurse, when she took his vital signs that morning, saw that his pupils weren't responding. He had had a stroke. . . .And while all of this was going on, my mother was in the hospital down the hall. . . .I was running back and forth between the two . . .on the Thursday morning, once he'd had a stroke. And we just asked if they would leave him on [Life Support] until the family could come. . . .Well, they got my mom from down the hall and moved her in to see him. Then my sister and cousin came. And then my aunt and uncle came. She [Neil's paternal grandmother] was in town looking* *after Brother at the time, so she and Brother came. And, [Neil's uncle] came, but I don't think he then came to see Neil. I can't quite remember why he came. But he was there; we had a little room that the family could stay, but I don't think he went in to see Neil. . . . We asked Brother if he wanted to spend some time with him, he could go there and he could speak to him. And he did. And he talked, talked, talked and stroked his hand."*

But immediately after Neil had passed away, Mother found little support. She had gone down the hall following his death to tell her mother, and when she returned everyone had left, leaving her to drive home alone. She recalls, *"I had my car there at the hospital and Father had his car. And then all of a sudden; I know I had stayed to talk to Mom. Everyone else had gone ahead to the house. Then there was me . . . [pause—crying, wiping tears]. You wouldn't think that would happen. I just went to talk to Mom."* She adds that in her shock, *"When I got home, I went to the neighbor's to tell them. . . .And then the neighbors brought food over. And then the people I work with brought food over. And then we had a pretty steady stream of visitors."* This, at least, provided Mother with some support to get through the days of the funeral. Mother's small family of origin was not able to provide very much support due to their own illnesses, and Father's family subscribed to a norm that said, *"Don't talk about it. Don't acknowledge it."*

It was the school community, and in particular, Neil's friends who provided the support that carried Mother through her bereavement. *"When we knew he was going to be taken off life-support, she [the hospital social worker] made all these phone calls for us, to let the schools know, so that they could prepare the kids. . . .And we had Honorary Pallbearers, his friends. . . . And I'll never forget at the graveside, they all stood like little soldiers . . . .They've been a wonderful, wonderful support. One of the things the kids did was, this must have been on a Sunday. He died on a Thursday. And then it was the Sunday they got together at one of the parents' homes, and they were all there. [some background noise while Mother pulls out the book from an adjacent bookshelf] And they put together this book for him. Each of the kids did a page with pictures and their memories of him. And then at the Service, when you go downstairs after the Service in the Church, they brought out the book."* The teachers supported their students in attending the funeral and taking an active role to remember Neil. One group of mothers gathered together the many photographs that had been taken through the years Neil attended the school and made them into a scrapbook, along with letters written by each child and teacher. Many teachers, students and their parents attended the funeral.

The first year following Neil's death, Mother reports, *"I barely survived"*. The family norm dictated that members endure—hold on to their grief internally and not mourn with each other; they tried to go on as if nothing had changed. When Christmas came a few months after Neil's death, Mother said, *"So we did go out [to Father's family]. And I had suggested to Father that we go through his stuff, that sort of thing, and take something out for each of the kids, in memory of Neil. We did that with his friends, too. We invited them to the house and I'd put out some things, and they could each pick something. . . .Father was a little reluctant at that, but he did do that."* But no members of the extended family spoke of Neil or used his name during the holidays they spent together. Mother adds, *"I'm a persevering soul. I did [use his name] and . . .it just, the topic just got changed. . . .They're not comfortable at all, talking about it."*

Depression led her to seek professional help. *"I suffered from depression, probably the last 5 years that Neil was alive. So that year, first year I barely survived."* It was with this help that things, *"just [started] to sort of crystallize. . . .The turning point was one time visiting the grave and, I don't know, somebody spoke to me. I don't know if it was Neil or God, 'What are you, what are you waiting for?"* Following this event at the graveside, Mother decided that she could no longer go on living with Father. *"We separated, but we continued to live together for almost another year, in the same house. . . .Brother was a big problem. I know we were a bit delusional, thinking of giving Brother some stability, I don't know. And Father wasn't. . . .Well . . .it was my decision. [He] was still in quite a bit of shock. Like he just wasn't really, even by then, he wasn't ready to move out. But I gave him a notice. . . .'Go! This is enough'. . . .And I certainly left the door open for reconciliation. He didn't want it to end; but he wasn't willing to do anything to change."* Mother feels she needed, *"Engagement, more effort into the marriage, more effort into doing things together and I guess not making decisions that affected us, by himself."* Mother and Father rarely argued, even when started having discussions about separation. She adds, *"And so there really wasn't--making decisions was very difficult. And I think what Neil's death changed for me is: I no longer had a son in grade 7 and [another son] in grade 10. I now had a son in grade10, by this time it was grade 11. . . And that changed . . .in that, in another year he would be in University."* She realizes that she had thought of divorce before Neil died. *"Well, the thought had crossed my mind. And then I'd just be so tired, [laughs] 'I can't even go there'. I didn't spend a lot of time dwelling on it."* Mother believed that Brother would not know of the impending divorce but, *"When we went in and talked to him, it just seemed like a big relief."*

In the year following the separation, Brother and Mother moved to a new home. While Father had been living on his own for many months since Mother and Brother moved, he had never created a spot for Brother in his house. Mother, even now, cries softly as she tells of the lack of space for Brother in Father's home. *"Father bought a house, so there certainly would have been place for Brother. And I certainly encouraged him to set up a bedroom for Brother. . . .And I said I didn't really see, at that age, that he would want to flip around, but if he wanted to, stay for a weekend, it was all right with me. He could fix up a room. But Father never really made room for him in his house . . . .He didn't have a bedroom there. . . .And then, the other thing Father said, somewhere along the line, is he felt Brother and I were very close, and he wasn't that close. So, that was ridiculous. Of course we were close. But . . . .[long pause —Mother softly crying]."* Even now Brother only occasionally visits Father. Mother believes that they have few, if any, conversations about Neil. Brother will not speak of Neil to her either, but he will listen if Mother chooses to remember him. *"[Brother)] doesn't talk about Neil. . . .I can talk about him and he'll give me a hug and. . .stuff, and be very sympathetic. But, no, he won't talk about him. Nor will [Father] kind of, won't".* Father and Brother do still spend each holiday with Father's family. She adds, *"I just thought the only time he's going to see his aunts and uncles and cousins, is if he goes there."* Although this leaves Mother alone on these occasions, she feels it is important for Brother that he attends because at least that way, *"He still has family."*

Each year a group of young people attend the yearly, graveside memorial service held by the religious group of which Mother is a part. *"You know, I try not to have expectations. . . .But they always, somebody does something. . . .And then, every year we have a little service at the graveside. This year, I never know, I just send out word to say, 'This is what it is. Anybody can come.' I didn't the first year. And then I heard that other kids; I invited his close friends and then I heard that other kids would like to come. And, 'Oh, why not?' So I just let the word out. And every year a different, I mean there are some regulars, but then it changes. . . And they come. This was at the end of April, so it was bitterly cold this year and so that's who came [she shows me a photograph]. And I found it really interesting."* These are the opportunities that Mother has to talk of her son and to remember him.

Mother is now in a new relationship; one where she is able to speak of Neil and share her stories of her *"gentle and soft-spoken boy."* While Brother has not engaged with her new partner, she hopes that he will, but recognizes that he is at a point in his own life where he must separate and build a life of his own. In the interview Mother described her today, five years after Neil's death, she has been able to move from her place of enduring to one of more active suffering, *"They [feelings] changed . . . my general numbness . . .is dissipating. . . .This year, for whatever reason, you know, I've been able to cry more. I've been able to, I guess, feel the loss. I just felt the loss this year. . . . I always miss him so much . . .[and feel] the gratefulness that he was my son and that he was in my life. "*

She realizes that Neil's death *"didn't cause it" [the end of her marriage]. You go on and stay married to protect the children. And you wonder if it is. And then this happens and you question things. I mean, it was hard for me to decide, but if that's what would work best for me and for the family... I have no regrets."* Without the opportunity to share stories, incorporate Neil's spirit, and make meaning of his life and his death Mother has remained *"numb"* for five years and it is just now that she is emerging from this enduring into suffering. She recognizes that she still has a ways to go before she can be more peaceful, if ever. She only hopes this will be so, and that this will be true for Brother as well. The rituals of her faith have taught her that *"Remembering – is acceptable."*

"*I will never know why a child must die for a mother to live*"
Time without Family Mourning:
The Story of the Baker Family

In the next story, Mother and Father Baker come together to speak together for the first time in the 27 years that has elapsed since the death of their daughter Helen. Mother asked their son whether he wanted to be part of the interview and he declined, stating that he felt he had no real memories of the event or of the bereavement that followed. It is interesting to note, however, that the couple did not choose to include their daughter who had been adopted following the death of Helen. It appears, as Mother relates in her individual interview, that Helen's death has become a private place that only includes those present in the family at the time of Helen's death, thus excluding Sister from the discussion.

As the parents talked together in the family interview, it is apparent that time has created different emphasis in their bereavements. As well, their individual interviews relate their separate processes. Father emphasizes growing up and the relationship he had with his parents. He provides this information as background to help the reader understand the functioning of this family at the time of Helen's illness and death. Mother emphasizes the difficulty she had mourning the loss of her daughter and the changes the death brought for her on a personal level including her eventual reformulating of self. While Mother and Father's story telling goes back and forth it appears during the course of the interview that they are relating their personal story more than a co-constructed family story; this fits with the characteristics of two people who were struggling to make sense of the death but doing so alone. At times, during the family interview, one parent adds or corrects information of the other, leading Father to remark, *"I'm providing stuff that you didn't remember and you're providing stuff that I didn't remember, and. . . .you kind of think that people cope, and cry, and grieve, and go on and start putting stuff back together, we didn't."*

Mother invited Aunt Choice to be part of telling the family story but in a separate interview from that with Father. Mother and Aunt Choice sat together during this interview and at times compared their memories. While Mother and Aunt Choice had spent many hours in the first few years following Helen's death talking about their feelings and supporting one another, it had been many years since they had spoken of Helen's illness and their bereavement. However, in Mother and Aunt Choice's interview, even though Mother has only the primary role of listener, there are times when Mother remarks on comments made by Aunt Choice and it is apparent that a new construction of the meaning of events is unfolding even at this late stage leading to a more complete understanding of the events. This is especially true when they speak together of the role played by Uncle Choice, a quiet man, whose stabilizing presence was critical but often understated at the time. It was only during this opportunity to recall their bereavement experience that Mother truly came to realize the loving acts performed so quietly by Uncle Choice. These interviews provide a window into the ongoing process of understanding loss in the context of family.

Telling the Story: The Spirit of Helen

"From the moment she was born you could tell that Helen had a mind of her own. She was a beautiful little girl with dark hair and dark eyes, friends called her the "Gerber baby." But she had a strong personality, always determined to have things her way, it could be a real challenge at times to be her mother, we would butt heads, but she was but my firstborn and always very special." Aunt choice describes a very close

relationship with Helen, *"I don't even know if you can describe her as a niece. She was just part of my family, I don't think I can delineate. The same as when Brother was little, he was sort of one of my kids."* She was Father's pride and joy. He loved being with her, teaching her new things. Mother feels, *"I think she was the only person who Father could open his heart to. He loved her so deeply and when she died, it was like his world came to an end."* Mother speaks of the relationship between Helen and Brother who was 18 months younger, *"Her brother just adored her. He followed her everywhere, doing everything she did, he would even let her do the talking--he was very quiet. But Helen was not. She was always rambunctious and ready to go and her brother would always go with her. When she died he didn't know what to do. But in the long run it changed him dramatically. He went from being a quiet, reserved little boy to an outgoing, friendly young man. He learned to be leader from her."*

Aunt Choice remembers her as *"a very confident, demanding little, young lady,"* the leader of her brother and cousin's, *"She was great; because she was that person out there leading them, guiding them, coming up with all of these creative ideas."* When Helen became ill at five years old and died, the small band would make up stories, reminders of the fun things they had done together. *"Helen was only sick for 9 weeks so it didn't give us any time to really get used to the idea that she was ill. And it didn't give us any time to get used to the idea that, that she was dying."* Father recalls the experience this way, *"You have a very sick child. And then from that point of time of April we went through this absolute vacuum hose type of experience just being sucked through until she died."* The family didn't speak very much about her illness to her. Father recalls, *"(She was) extremely sick and confused and yet very astute little girl. And yet I think, in retrospect, (she) knew what was going on at some different level that I certainly couldn't understand. I remember certain times with her were she would just. . .say something or look at me at a way. . .that either, asked a question or just kind of made a statement. One of them was when after chemotherapy, she reached up to brush some hair out of her eyes and it pulled out. And she just looked at me. It's hard to say what she was thinking and it's hard to understand what I was thinking too."* Mother recalls another incident during her illness when Father was driving her into an appointment for radiation, *"She turned to Father and said,' I'm trying to be brave Daddy. Because I know if I am brave it will be easier for you and Mommy.' To this day thinking about that breaks my heart. But that was the kind of kid she was, always strong, always* *ready to do what needed to be done. She was so brave, I wish I could have been as brave."*

But all those memories of the strong little girl became lost for a couple years after she died. Mother said, *"we didn't talk about Helen. . . .It wasn't exactly taboo. But it probably was as close as we could've gotten."* As a result, her story was lost to the family and lives only in the separate memories of Mother, Father, and in very minor ways, because he was so young, in Brother.

The Family

Twenty-seven years ago, before Helen died, the Bakers were a very traditional family with two children, one girl and one boy. Father was the breadwinner and Mother took care the home and children while working part time. They appeared, to all who knew them, to be a happy family; one that others would never imagine could become divorced. Mother says *"When we told our friends that we were divorcing, they were shocked. On the outside we looked like we were this happy couple."* However, shortly before Helen became ill Mother became discontent with their family life, she was beginning to realize that she had given up who she was when she married Father. *"I was REALLY unhappy. And I wasn't going to do this any longer. I wanted my life back."* The family norms set at the beginning of the couple's marriage needed readjustment but when Helen became ill and died this could not be accomplished.

Through the benefit of time, Mother now realizes that at the beginning of her marriage to Father: "I just didn't want to figure out what my life was going to be about and so I simply decided, *"'Oh, well, I think I'll just hang my life on this guy's.' And so in that sense it caused this kind, of very, very strange dynamic, where in some ways I was…somewhat living your life, but then if I didn't like that life, and I think there were lots of things I didn't like about it, I would get mad. So, catching you up cold, you might agree, putting you in a double bind, saying, 'OK, you decide, but I have the right of recall. And I can blame you, if I don't like what happens.' So it was set it up in such a way…that it was going to fail, period."* Father agrees, adding, *"We never fought. But we sure as heck should have. . . .I think we were just two nice people who. . .didn't see things in the same way. And just (short pause). And it just didn't work."* As a result when Helen became ill, Mother states *"it was coming to a point where it was going to go one way or the other"* and Father agrees adding, *"Yeah. We were approaching a hill."*

The couple had been high school sweethearts. On finishing university they married and moved 2000 kilometers away from family and friends. They established their new home, made new friends, and had children. Most of this work was done without really thinking about who they were or what they wanted as a couple and as a family. Father states, *"I see us as two teenagers who came together, and did all right. And certainly in all this, there were some tremendously good times, and a lot of fun, and a lot of stuff. But, we never grew together. We started growing up apart. And when the time came, when I could see you pulling to be your own, I put up barriers like something fierce."* As Aunt Choice looked at their relationship from a distance, she observed, *"And I think Mother's relationship with Father was okay if Mother did whatever Father wanted her to do."*

Father had learned, growing up, to avoid expression of strong emotion and conflict and he carried that learning into their marriage. Mother states, *"Communication was always a problem for us. We never talked about anything other than routines. . .we never really, never fought. And I say it this way, you can correct me if I'm wrong. But I say that you wouldn't fight. . .that if we disagreed, chances are, you would walk away. And you had a way of making it very well known that the subject was closed and I accepted that."* Father agrees and adds, *"Our communication skills were not strong, at all. And certainly the death of a child didn't make them any better. So then I would build up just all sorts of walls and. . . play the male power cards. And that's how we ended up where we were."*

Adding to this problem was the interference of Father's parents and the expectations they held for the young family as revealed in this exchange during the family interview. *"Mother: but we had. . . a lot of pressures on us. Certain pressure to be a certain way. Father: Yeah, nothing was spelled out, do this, do that, or anything like that. But an overall expectation that you will conform in the following ways. And financial pressure was used to exert that. And that had been a pattern that I had grown up. And I think there were times when we tried to break it. I think we could see it. . . .There were arguments with my family about it, but there was never really a will that, particularly that I had, to break it."* Mother continues and further explains that their family norms were simply a continuation of the norms in Father's family, *"Of course, your parents didn't fight either. They would just walk away too. God, your father would walk away at the slightest disagreement."* Father adds, *"Oh, yeah. Their relationship was even more bizarre than* *ours was!"* Mother explains, *"So then when Helen died, or got sick, we had no capacity to talk about what was happening…any of it at all. NONE!"*

In the nine weeks from the time of Helen's diagnosis of cancer to her death, the couple attempted to keep things as normal as possible in their home, Mother states that when Helen became ill the family had no way to talk about what was happening, *"And we were very much in a denial mode I think up until the last week. And although from the first week that she was diagnosed, I was present when they did the scan and I could see this tumor in her head, and I knew that nobody survived with that size of a tumor in their head. So from that aspect, in my head, I knew that she wasn't going to make it, but in my heart, of course, I was hoping she would. And every part of us as a family at that point went into assuming that she was going to get better."*

Maternal grandmother came to help during the time of diagnosis and then again in the last week of Helen's life. She provided a stabilizing presence for Mother, who then did not have to worry about Brother's care. Since Grandmother was a strict disciplinarian, the rules for Brother were different from what he normally experienced, the 3 1/2 year old, however, seemed to manage and took the absence of his parents, who were spending long hours at the hospital, in stride. The family was also supported by Aunt and Uncle Choice. Aunt Choice spent many hours at the hospital supporting Mother when Father was *"avoiding"* the difficult situation by working long hours. Aunt Choice states, *"Father had sort of withdrawn in that last few weeks in the hospital."* Uncle Choice lovingly provided care not only for his own two boys but often for Brother as well. Aunt Choice speaks of her husband and adds, *"I mean, like Mother said, he was a quiet person, so a lot of times it was just, he was just there. If I came home or if he was at your house or whatever, he was just there and he would ask how we were and mostly it was how Mother was. Mostly it was how Mother was. We (Aunt and Uncle Choice) talked about Brother and his adjustment and what we sort of perceived and how kids seem to just carry on."* Because Mother and Father had no extended family close by, Aunt Choice's parents had come to play a role as surrogate parents to the young Baker family and, they too, were supportive in providing care to Brother. While other friends brought meals, visited at hospital, and listened when Mother needed to share her fears, it was primarily Aunt and Uncle Choice who provided this support. Aunt Choice adds, *"I felt very protective to Mother um, (pause). . .more towards Mother than Father. I remember feeling really frustrated with some of those people who hadn't been there* *when she was in hospital and then those people kind of coming into the picture afterwards."*

Father was unable to talk about what was happening for him even though friends tried to be supportive. *"I would say that some of my. . .staff had almost quasi-family role. Certainly, P.Y. . . .tried to do that. . .and took on almost a surrogate father role for me."* But, Father felt that he needed to *"be strong for his family"* and being strong meant not speaking of his pain, While the Baker paternal grandparents came at one point in Helen's illness, with the intention of providing support to the young family, the struggle of their only granddaughter and the problems caused by her disease was *"devastating"* for them and after a few days they were unable to cope and retreated home.

Even though Mother and Father sat at the bedside of their comatose child for a week, they were shocked that death came so soon. On the day of her death, Mother and Father remained at their daughter's bedside, but returned home for supper and to check in on Brother. When they returned to the hospital a couple hours later, Mother remarked on the way in, *"I'm so tired of coming here. I wish we didn't have to come back again."* But on hearing the news that Helen had died, in shock she thought, *""WELL THIS ISN'T WHAT I MEANT BY NOT COMING BACK!"* Father *recalls "And so she was just laying there. And that really hit me. Just kind of, OH! OH, MY GOD! THIS HAS COME TO AN END!"* The couple stood by their daughter's bedside for a few short minutes before Father walked away to the window. Mother recalls, *"You walked away from the bedside very quickly, I think. My memory is that you walked away quite quickly and stood at the wall, window, and stood with your back to us and when I came over to you, you didn't turn around."* It was at that moment that Mother feels that Father left the family. He recalls, *"I remember that, again like having, being in totally uncharted waters. It was like being in a cloud, being in a daze."*

Mother and Father returned home to tell Grandmother and make calls to let others know that Helen had died. Mother recalls when she returned home from hospital following Helen's death, *"and my mom gave me a hug and my mother was crying. And my mother never cries. Up to that point I had never seen my mother cry. And I said to her, "Don't do that to me, cause then I'll start, and I'll never stop!"* Later, when telling Aunt and Uncle Choice, she repeated this behavior, so afraid that if anyone cried, she would give in to her feelings of devastation. Aunt Choice recalls, *"I remember Father and Mother parking on the other side of the street. I hadn't been to see her that day or the day before and I do remember when they came I thought, "Oh my gosh! I should have* *gone."* I remember Mother crossing the street and coming up to the house because I saw Mother from the window. That's in my mind....And telling us then. I do remember that....Actually, what I remember is being really upset and I think actually Mother's comment was *"Oh, not you too!"*

When Paternal Grandmother and Grandfather were phoned, they informed Father that they would not be coming for the funeral. They cited the cost of travel as the factor in their non-attendance, but even in that moment, Mother and Father were well aware that these grandparents had no capacity to deal with the strong emotions of grief or offer them support. Father was devastated. He recalls *"I never felt so alone in my life. And so ah, just ABANDONED. And so I went through the whole funeral experience, with this feeling that...there's a line from the Godfather, 'you gotta be strong for your family.' And this kind of false sense that I had to be this rock that was to be so strong to have everybody hold on to, and feeling this, totally other worldly. Because my own family wasn't there to support me."* Aunt and Uncle Choice would talk about the situation and Aunt Choice recalls how shocked they were at these grandparents weren't coming to the funeral to support their son and his family. *"We talked about Father. . .(and) when Helen died and his mom and dad didn't come, we did talk about that. And how horrific that was and how blatantly abandoned he was, I think. I think that was the biggest thing. And for us I mean--what were we 30? How your parents could say they couldn't afford to come to their grandchild's funeral, I think we did talk about that. That whole business of how awful it was."* Father's thoughts and feelings set the stage for what was to come.

Within the first week, the young couple emptied Helen's room and repainted it. Mother's family attempted to provide support with several members attending the funeral. As these family members watched Mother and Father undo their child's existence by dismantling her room, they cautioned them that it would be harmful. But in their shock, Mother and Father could not heed this warning and did the only thing they could do at the time-- pretend that their child had ever existed. All reminders of their daughter were given away, with only a few things put in a box that would not be opened for many years to come. Aunt Choice recalls how odd that seemed,but wonders if it was in keeping with societal expectations of the time, *"I think because Helen's things were cleaned up so quickly. . . .Brother had a lot of – I think the message was, 'Okay this is done.' and I don't know what went on in the home but I, 'This is done and, and we're moving on'. . .I mean that was always a little weird, so I think it was kind of brush your hands off (AC motions that action). And I don't know where that came from. . . .So I'm* *not sure, but I also think at the time probably it was how we, as young people, would have thought of as what was the best way to deal with kids. What did they understand really?"*

Although there was no strict rule about using Helen's name in the house, it did not frequently occur. Mother says, *"So, it wasn't exactly taboo. But it probably was as close as we could've gotten."* Brother was the only one to use Helen's name and tell her story but it seems he quickly learned that doing so brought pain to his parents and within a few months, he too stopped speaking of Helen except with his cousins (choice). Aunt Choice reports, *"I know the kids used to talk in the backyard and pretend Helen this and Helen would say that, so they did talk about her. . . .there wasn't lots of conversation because they were young, but it would be, I mean Helen was still mentioned in their conversations. By Brother and Cousin 1 yeah. Cousin 2, of course, didn't say a whole lot. He was just 2. I don't think he (Brother) asked me stuff. I remember them playing probably in the backyard or in the kitchen, and. . .all I remember is that pretend Helen says this, or pretend Helen did that – that kind of thing. You know how kids go through that time period where everybody is dead when they played. You know, this person died, that person died. I do remember that, but whether that was more coincidental to that developmental age, because I remember Helen playing that too with her Barbies. . . .Yeah, so I don't think he specifically asked me questions but I do remember us sort of mentioning her name and things like that but again. . .I think it was one of those things where we didn't really know (what to do)."*

In the months to come, Father would spend increasingly more time at work while Mother was at home trying to maintain her family and pretending that nothing had changed. She recalls, *"We carried on. We pretended to carry on life as it was, as it had been. And so the only parts of our routine that changed, in some ways, was that Father really involved himself more and more in work."* (*But) the one thing we did is, that never, rarely, did we ever eat dinner at home again....we rarely ate dinner at home. We rarely sat down and as a family ate dinner. And before that we always had dinner together."*

Aunt Choice suggests that as Father left the family, Mother and Brother (and later Sister) were increasingly incorporated into their family, she describes this, *"So I think probably not very long after Helen's died, you could probably track it, you see him leaving that that circle. So maybe Mother and Father and us are part of an extended family and then you can see him pulling out of Mother's immediate circle and again further and further away from that circle. . . .All of us just broadened our walls and that's* *where Mother is with us. And Father was, eventually, not in there at all. (used the circle diagram "resource of people" to visualize the change)."*

Later in the summer, Father's parents came to visit the mourning family. But since norms have been so strongly constructed in this family that did not share their feelings, the family did not know how to manage even the simplest routines during the visit. When the grandparents went to Helen's grave without including Mother when she had asked them to include her (since father refused to go and she did not want to go alone), a huge argument ensued which eventually led to Father telling his parents to leave their house and never returned. The young couple did not speak to these grandparents for months, but when telephone conversations resumed Father refused to express his hurt to them. He also *"ordered"* Mother to never speak of the topic again. A major turning point occurred in the couple's relationship at that time. Mother came to realize that piggybacking her life on to Father's was no longer good enough. *"I was tired of being the scapegoat. I decided that I was no longer going to follow their rules-- it just wasn't good enough, we all ended up hurting too much in this ludicrous way of carrying on. I don't think, at the time when I refused to accept the blame for not allowing his parents to visit, that this would change my family so much, but I knew I was not going to be hurt like this anymore. I gave him notice, at that time, not realizing what a disastrous effect it would have on our marriage in the long run. But now I realize, 27 years later, that it was the best thing that could have happened. Had I accepted remaining in this position, I would've died a slow and painful death-- maybe not so slow, I became so suicidal anyway, maybe that's what would've happened had I 'not rocked the boat'."*

Also, within weeks of Helen's death, the couple had applied to adopt a child. While Mother feels that Sister was a *"replacement child"*, Father does not see it this way. Mother reports, *"When Sister came, he (Brother) was so happy to have a sister. He tried so hard to be the big brother to this child who took (so much) energy."* Aunt Choice recalls how she and her mother, who had also experienced the loss of a child were concerned about the speed of the adoption application, *"I know when Mother and Father were talking about adopting, at that point in time, because even Uncle Choice and I were questioning that, you know. Like, gosh. Because from our point of view it was, they were replacing her. That's where we were. And 'Is it too soon?' And all of those types of things. And I know my mom said the same, 'I hope they are going to be okay, it's wonderful to expand the family, but I hope it's enough time.'. . .But, yeah, I think everybody had that same kind of sense of 'WOW…it's fast, it's quick.'"*

Father distanced himself even more from the family after Sister arrived. Mother recalls *"You weren't home very much then. . . . You would stay at work, and if you came home, you most of the time you would fall asleep. You would have supper. . . . You would come home for supper, sit at the table, and then go in and lay down and fall asleep."* Father agrees, adding, *"I dropped out. . . . Yeah, out-of-control. Because in terms of my participation, especially in household chores and things like that, it got to be particularly bad at that time. And I remember arguing about that too."* Mother adds, *"Yeah, we tried to fight then. . .but we weren't very good at it."* Aunt Choice adds, *"That's probably when he really did leave, when Sister came. And then again rather than acknowledge that you know, that this is probably not a good thing. I think in that point in time that was sort of like driving a chisel in and I think then I think he moved further and further away."* Their norms did not assist them in restructuring their family and instead led to a divorce. Mother adds, *"The end of our family. And as such the end of us AS a family."* And from that point, it was two separate families. The Bakers had not created a space for grieving as individuals or for family mourning but had simply created distance. They *"just simply had no words"* to convey to one another the depth of pain that the loss of their daughter brought to them. *"The only night that I ever remember us crying together was the night when she went to the hospital when she had that shunt put in. . .and never woke up again. And they phoned us to tell us to tell us she had started she started seizing. . .and I remember, it was about two o'clock in the morning, we got home about one and they phoned about two, and told us she had started seizing. And we did lay in each other's arms crying for about an hour. But that's the only time."*

Today, 27 years later, Mother and Father have both remarried and structured new families sharing Brother and Sister. Brother has told Mother that while he remembers very little of the time following Helen's death, he has felt that growing up he had one family living in two households. He thinks that it was the hard work that Mother and Father put in learning to parent more productively following divorce than they ever had when being together that allowed him to feel a sense of family.

Both Mother and Father have worked hard to learn from their experience of losing a child. Mother remarks, *"I finally came to think that this occurred for a reason. The expression I would use in those days and, and one day I remember I was sitting on a park bench and I thought, "You know this is so unfair." And I was definitely stuck into that place for a while thinking this is unfair. How could I have got this, I must have forgot to do this and all of that kind of stuff. I was really into that big time for a while. And then it* *kind of came to me that it's not fair that a child has to die so a mother could live. But, that's exactly what I would say had happened. That, for me, my coming to terms with why Helen died, why did she have to die. Had to do with that idea that she wasn't put on this earth to live long, but she was put on this earth to wake me up, because I think before that time there were a lot of things that I was just, I was really. I gave my life over when Father and I got married. I gave my life over to him. Not in a good way. And, then here I am suddenly it felt like I was without anything. And even, Brother, I mean, I know I held onto my life, because I was suicidal at some points in that. And I held on I think for him. And thank goodness he was there, because I don't think I would otherwise. When Sister came. . .the first year or so, I mean there was no way I was letting her in. So here's this poor kid who already had enough misery, going through another year of it with a mother who would physically take care of her but that was it. Do nothing more. So it was at that stage I think, I thought, 'Okay, you know, if she was put here for this reason, I better wake up and better do something about it.' I think things really changed a great deal at that point.*

Father recalls of his struggle, *"I kept things, (sigh) my memory is that I kept things so firmly bottled up inside that there was just no way that I could be, that I could express what was going on in me. I am sad about that. I am really, as you look back at different phases of your life particularly as you reach middle age. And you look back and I'm really sad I wasn't able to talk about it at that time. But we learn what to do from the way we have lived and from the influences of others on us. And certainly the baggage that I came with in terms of family, particularly my father,. . .came at a heavy price and one of them was you just don't talk about your feelings. You just don't show stuff, you just keep soldiering on and that's the way that you're a good man. And that's false. That's the way you're a hollow man. And so. No, I didn't until 3-3 ½ years later that I started being able to talk more freely about it. And then as time has gone on, . . .it's one of those things in terms of the therapy of tragedy, I would say. Now at different times and in different situations I can talk very openly about what happened to me. The whole experience of losing a child and again it's to me, it's something that I do for others and, it has come up numerous times in my teaching where with a given class at the right moment, at the right time, I can talk about this with them. I just kind of say to them, and these are university kids or older senior high students. Just kind of say, 'life is going to deal you things that you don't expect and you need to be prepared and you need to have to have different support mechanisms or you can come to grips with what's going to* *happen to you.' And tell them the story, tell them some of my failings in the situation. And let them draw some conclusions from their own point of view on it. . . .I think there has been quite a change in my life over time, I think. I hope."*

While it may be that the details fade over so long a time, the impact that Helen's death has had on this family is enormous. While both Mother and Father realize that the norms that they held at the time Helen became ill predicted an impossible course for their family, there is some regret. Time alone did not provide space for them to readjust their family norms and create a space for family mourning.

The Stories of Families Sharing the Work during Bereavement

In contrast to the first four family stories, the remaining nine family stories describe the experiences of families as they undertake the shared family work during bereavement. As with the first four families, these nine families are at different points in their process. Some have only begun the family work while others expressed a view that their work of grief and mourning is complete and they are now different as a family then before the death of their child.

"I'm just trying to listen for the laughter"

Family grief:

The Story of the Damant Family

The story of the Damant family is told by Mother, Father, and Brother 1 with Brother 2 listening in another room. As the family story is told, the family norms of respect and parental leadership are evident. Father takes the lead in the family interview, perhaps, because he is the one who can speak most clearly through the raw feelings that are present for this family. In the first part of the interview, Mother sits quietly, gently crying. When she is able to speak, her words mingle with her tears. Brother 1 is an adolescent, who in his individual interview finds it difficult to put into words is experience, hence this is reflected as well in the family interview where his few comments occur as a result of direct questioning. However, when he does speak, Mother and Father listen, giving the impression that they value his input. Mother welcomes in Brother 2 as he enters the room occasionally to 'check in' and make sure his family is okay. He would appear in the doorway when the talk turned to emotionally-laden topics. Sometimes this would be a simple peeking in and on two occasions he came to the table and sat down, interjecting thoughts about his project occurring in the other room. The family turned their attention to him on these occasions, but once his need seemed satisfied, they would return to their previous discussion. Much of the family story relates the events surrounding the death of Ben and the serious injuries of Brother 1. But they are also able to relate how these events have changed their family and their life together. As the interview proceeds, Mother is able to join Father in sharing her thoughts and feelings and, together, they construct a family story of bereavement.

It is in the individual interviews with family members that the raw pain of Ben's loss is seen and felt. Their grief has not had a great deal of opportunity for expression due to the need to endure in order to support Brother 1's recovery. In these interviews Mother and Father uses powerful words to relate their experience. In the second interview, when my visual representation is shared with them they both strongly relate to the concepts of enduring and suffering, Father commented that suffering is his present reality now that the need to endure for Brother 1's recovery is over. Brother 1 was invited to draw a picture of his grief, but declined, choosing instead to talk at some length about Ben and the important role his brother played in his life.

This is a family where quiet occurs so that they can absorb the impact of Ben's death on their family. They have begun working together through the quiet ritual of going to the cemetery together; a time often filled with silent personal reflection. They are becoming aware of the need to tell Ben's story so that as a family, they can create his spirit. The spirit that has been symbolized in the crystal angel that hangs in their living room.

Telling the Story: The Spirit of Ben

"Ben was; he was a kind, giving, gentle, loving, loving little soul. He'd bend over backwards for anybody." He loved to cook while Brother 1, Mother, and Father would spend long hours out of the house doing fieldwork, Ben supervised Brother 2 and fixed meals for the family. Now it is only Mother and Father in the fields while Brothers 1 and 2 remain in the house. Ben was the link between Brother 1 and Brother 2. Now, without him, Brother 2 spends a lot of his time alone playing quiet games. Mother remarks of the change in Brother 2 since Ben died, *"He's different . . .at times he's quiet and reserved. He doesn't want to play with Brother 1, but goes off by himself to play by himself. There's that middleman missing. Brother 1 is so much older than he is. And that was, if he wasn't playing with Ben, he was playing with Brother 1. . . .As well the dynamic between the boys has changed."* Father continues, *"It really changed the family dynamic. . . .You'd*

always have the two for one thing, and the other left out, always. When you have three, it seems like it was always one was right on two wrong, or two were right and one was wrong."

Brother 1 enjoyed taking an opposite side to his brother, *"He was pretty cool. Yeah. He always wanted to do things. He was always active and everything. . . .He was very sharp. . . .I looked up to him. . . .That was what was really excellent; we were pretty much opposites. . . .He totally liked different things and argued about it, but we agreed that each of them was, in their own way, good. . . .He always just seemed to make things better. [INTER: What did you like to do it together most?] Arguing. For both. Arguing isn't the right word; it's debate. . . .He would always win."*

Although Ben loved to hold a good debate with Brother 1, he was not a fighter. Father remembers, *"He was a big kid. He was the biggest kid in his class, the second biggest kid in his class . . . .And he could have been. . .mean-spirited and there was nothing anybody could have done about it. But he wasn't. . . .He was his mother's soul . . . .He was kind and loving and gentle. . .that's what he was."* Father tells a story about just how big a heart his son had. *"I'll tell you in February of last year; Ben had a lump on a gland in his jaw. And while we were going for different tests, he had to go for ultrasounds. He had to go for MRI, things for diagnosing what this lump was. We were reading an article about this outfit that you grow your hair; it's called Angel Hair for Kids. And your hair is then given to kids that have been burned or kids, who lose their hair to radiation therapy and what-not, get a wig made from human hair. And he just said, 'Let's do that, Daddy. You know, let's me and you do that.' So we were; I'm still in the process. He was in the process of doing that."*

The family longs for the presence of their son and brother. This year, Ben's birthday was celebrated with the building of a special memorial garden in the yard on the side of their house where the boys most often played together. Mother and Father sit on a bench in the garden talking about;*"Do you remember when we did this?"* But for Mother, it is a melancholy time as she finds, *"I'm just trying to listen for the laughter."*

Father has felt Ben's presence. He describes it as, *"A shudder goes over your body, almost like he's sitting beside you . . . .It just seems like he's there with you."* He relates an experience which occurred on Christmas Eve. *"I think I went to bed about one o'clock. And I know it had to just be a dream; I know it had to be. But I woke up and there was a little boy standing at the foot of the bed. . . .I know it . . .but yet. . . .I know that's just a dream and it's. . .well, it felt real, but I know it had to be a dream . . .*

because, again, it couldn't. Well, I shouldn't say it couldn't have been. Maybe it was. . . . He was just standing there. . .It's not like I could see his face or anything. It was just there was a boy, standing at the foot of the bed. . . .I didn't get much sleep for the rest of the night, that's for sure." When he feels Ben's presence at other times, he says *"I just talk to him. . . .I just tell him I love him, tell him I miss him, tell him I'm sorry for any time I gave him heck for doing whatever. . . .Tell him how much I miss him, how much I want him back".* But Ben never answers him. *"You know, I'd love to have one of these moments where you speak to somebody from the other side and they tell you they're in a great place and it's. . . .'And don't be sad for me, I'm fine.' But. [He believes] it's Ben's spirit wanting to be next to us or be near us, just to be with us. . . .And to let us know that he's all right and he's just there to comfort us, kind of thing. . . .But then, part of me, the other half of my brain kicks in and says, 'You know it's just you're feeling sad,' and certain hormones are going around all of a sudden, so the logical side of my brain kicks in and says, 'You know that's not really what it is. . . .But the other half of my brain just wants it so bad for. . .for his presence to be there, but. . .'"*

They have not had time, in the seven short months that they have all been present at home, to make meaning of the life and death of Ben, but they are trying. Father struggles to understand why such a kind and gentle boy's life was so short. *"So I guess the sense to me in Ben's life, was just that Ben cared for others more than he cared for himself. . . .It brings me pride. . . .I just wished that he could have lived to 100 years old doing the deeds that he did every day."*

The Family

The story of the Damant family is the story of a family on hold. Ten months after the tragic, family members are struggling to understand how their family was so suddenly changed and what they can possibly do to give it structure and meaning again. The family's three boys were coming back from a short holiday with Grandmother [paternal] when the car they were riding in was struck from behind by a careless driver. Ben was killed instantly, and Brother 1 was severely injured requiring immediate air transport to the nearest city, neurosurgery, and 80 days in acute and rehabilitation hospitals. Brother 2 received only minor injuries as did Grandmother. They were taken to a local hospital emergency ward and immediately released.

Mother and Father were out in their fields and viewed some commotion at a distance on a near by highway. They both, immediately, experienced a sense of dread.

Mother states, *"Father and I were in the field. And you can see the highway from the field. We knew there was an accident because the cars were lining up . . . .And we phoned Grandma's phone, and there was no answer. [sighs] So we were, just felt uncomfortable and I wanted to go and check it out, or see what was happening. And as we drove by the driveway, the neighbor lady and the fellow who drove us there were in the driveway. And you could just see by the expressions on their faces, and I remember him saying that there was an accident. [pause] And it was uncomfortable because you knew there was something not right. . . .Well, as we got closer, I could see it was a white car. They were in a white car, but as I got almost to the accident, it didn't look like the car. And I thought, "Maybe it's not my children. Maybe it's not." . . .But as I got out of the truck I seen Brother #2 and I knew it was. [crying softly]"*

Mother and Father immediately realized that one of their children was dead and another trapped in the car and severely injured. The emergency crew took them over to Brother 2 and Grandmother while telling them that Ben was dead. They were not allowed to approach Ben's body nor go near the car where Brother 1 was trapped. They waited at the scene of the accident until Ben's body was taken to the local morgue, Brother 2 and Grandmother were transported to the local hospital, and Brother 1 was airlifted to a city hospital. Leaving the accident scene in their state of shock, Mother and Father were driven, by a friend, into the local town.

After being reassured by the emergency room staff that Brother 2 and Grandmother were all right, the couple first made arrangements for Brother 2 to be cared for by his paternal uncle and aunt before going to the morgue to say their goodbyes to Ben. They then left for the city to be with Brother 1. Throughout their car ride, they could not help but wonder what awaited them on their arrival and feared that perhaps they had lost a second son.

On arriving at the hospital, they were told that Brother 1 was in critical condition and would require neurosurgery and may not survive. For the next five hours, they sat in a sense of disbelief that their close-knit family could so suddenly be changed. When the neurosurgeon appeared, Mother and Father were overjoyed to learn that Brother 1 would survive and even make a good recovery—but it would take a lot of time. Their joy in this news was interspersed with their pain and deep sorrow in the loss of Ben. In the many weeks to follow, Mother and Father would again and again feel these mixed emotions-- joy in the survival of one son and pain in the loss of the other-- together with feelings of guilt that this was so. Father tells us, *"We really couldn't focus on our loss. I* *mean we were pulled in three different directions between being at home with Brother 2 and running our farm, and thinking about Ben and what we've lost, and being with Brother 1 in the city and helping him recover."*

Mother and Father began a very difficult journey of separation out of necessity. Brother 2 was at home, alone in a sense--without the family he knew--but warmly supported by Uncle and Aunt who stayed in the family's home caring for him and handled all the calls of support that were pouring in from family and the community. After three days, Mother and Father traveled home to make arrangements for the burial of their son, but had to do so hastily as Brother 1 was still in intensive care and they wanted to be there when he woke up. They were assisted in planning the funeral by their minister and close family members. They returned to Brother 1's bedside until the day of the funeral, a day filled with community support but one where Mother and Father were somewhat in a daze from exhaustion. They can remember the general unfolding of the day but memories are *"somewhat surreal"*. The next day they returned to the city with Brother 2 and began to assist Brother 1 on his long road to recovery. When Brother 1 saw only Brother 2 at his bedside he knew something was wrong and asked about Ben. Father told him that Ben had died in the accident, but Brother 1 was too overwhelmed (or too drugged) to comprehend. He reports that, even when months later he returned home, Ben's loss did not seem real and it took a further three months for him to really comprehend that his brother was dead and would not be coming back.

Brother 2 returned home into the care of Uncle and Aunt who continued to stay at the house with him until Brother 1 was stable enough to be moved to a regular ward from ICU and Mother or Father could leave the bedside. During this time, and for weeks to come, the family was further supported by maternal Grandmother and Grandfather who traveled from their home 500 kilometers away to stay in the city with Mother and Father. Family members provided space for them in their homes in the city and offered space to Mother and Father, but most often the couple stayed at the hospital with Brother 1. This began a difficult three months of separation, but it was luckily filled with the support of family and friends in the community, seen in the many kindness acts that occurred. The family found that their greatest support came from the things that others have done for them. Father reports that while much of what people would say were *"all cliché. It is when anybody [said] 'If you ever need anything,' and didn't just say it, but did it,' that mattered. [He adds], You know, little things that people did, like that. One lady . . . just looked at me and just said, 'You know, I'm not going to say anything.' And she just* *gave me a hug. She said, 'Because words are irrelevant'. And those kinds of things really are; those are the things that stand out to me."*

It was the beginning of the school year, so when Brother 1 was a bit more stable at the hospital, Father traveled home to organize Brother 2 for school and take him to his delayed first day. The teacher knew the family well, as often occurs in small towns, and was particularly understanding and compassionate of Brother 2 throughout the school term. It was also harvest time--the busiest time of the farming year-- but Father did not even remember that the crop needed to be brought in while he was attending Brother 1 at the hospital. It was only on his return to home and, hearing the over 30 messages recorded on the answering machine, that he realized that the work was already being done. Two of his uncles had organized a crew to harvest the crop. Aunt and Uncle further organized the feeding of the workers while continuing to run the household and care for Brother 2.

As the weeks went on, the family established a routine wherein one parent was at home with Brother 2 while the other was at the hospital with Brother 1. *"It's almost like we became workaholics for his recovery. . . .We believe our constant being there is the reason why he is where he is already."* Father found that being at the hospital provided a distraction to his grief, *"We could focus there . . .and that's why when we were at the city or in the hospital, it was almost like it wasn't; nothing else around us mattered. . . .But when you left the hospital, it was like a sack of bricks landing on you again. . . .It would be the time when I would be apart from Mother and not at the hospital, and vice versa when she would be here. . . .And you could tell it just in each other's voices on our mike phones when we would talk to each other. The person at home, you could just hear it. . . . The difference just in the. . .solemness [sic] in the person at home, versus the, I don't want to say, but the person in town was definitely. . .less solemn, I guess. [Father adds], When you were in the city, it seemed like this didn't exist, the farm, Ben's death. You know, I mean it existed, but I mean it's like in your mind it's, 'I'm here. I can focus on helping Brother 1". . . .And then you come home to a house where there was five and then you come home and then there's two. And then, after 8:30 in the morning, there's one, because Brother 2 would go to school and you would rattle around doing whatever. . . .And the cows had to be fed. I mean there was things, we didn't have any choice . . . you can't expect [other people] to do everything for ever and. . .you just had to do it yourself."*

While it was difficult to focus on the household and farm chores, the space created at home in these forced circumstances gave Mother and Father the opportunity to feel Ben's loss, as they took turns being at home. As Father explains, *"I do believe I needed time to be alone and never really had any of that. There was all; in the hospital, it was always people there, coming to see [and] there's always staff at the hospital. They are around you . . .and I don't know how significant the alone time is. . .but you unwork some of the stuff that you had to hold in while you were surrounded by other people, that's for sure. The sorrow. The anger. Crying and then, sitting in the cab of the tractor screaming, just screaming . . . .Swearing. Cursing. Questioning, 'Why?' . . .The bargaining: 'Send him back and I'll go. . .take me instead. Take everything I own. Take. I don't care. I'll live in a ditch, just send him home."*

Another emotion-filled difficulty has been the break between Grandmother (paternal) and the couple. Unfortunately in this tragedy, the relationship with Grandmother was severely damaged as Mother and Father blamed her for not protecting the boys sufficiently. While they recognize that blaming her is an irrational belief, their heads and hearts have not been able to form a more realistic view and now, even 10 months later, they are still estranged. Father states, *"I mean, the accident was his fault. But [pause] Ben was with her, and she didn't bring them home safely. . . .And it's, I understand that she's hurt and that she realizes, I mean it's not her fault. . . .But it's something that we'll have to work through."* In her distress, it appears Grandmother focused more on her own pain and could not be supportive of her son and his family. Mother adds, *"It's difficult to visit with her. I mean, I know Father said earlier, 'We know it's not her fault. "*

Father realizes some of his feelings are related to his anger at the situation and at himself. He wants to resolve them. He states, *"Well, you go through the what-ifs. What if she'd just got off the road? What if? We did not want the boys going because it was the long weekend was coming up and we don't like them on the roads on the long weekend. . . .But, it was kind of: they didn't get to go on a trip with Grandma this year and you know just when we were at home she was gone. And when she was at home, we were doing something or we were gone . . . .It was the last chance for them to spend the, you know, there was no trip with Grandma. So it was kinda, "Well. Okay. I guess you can go, then." . . .So maybe part of my anger that's projected at her was projected at myself, in the fact that if I'd have just said no. . . .He would still be here. . . .You go through 10,000 of those what ifs. I also know that we are working our way through that.*

She is aware of everything that I feel and. . . .And I know that we have to get rid of this, because it's just a poison. And I know we have to get rid of it because either of us can pass on tomorrow. . . .Anything could happen and I don't want either of us going to wherever not having that resolved." The family has made efforts to reconnect with Grandmother and things are improving. . .Still, *"We're more distant now . . . .She's not responsible for his death, but she was, he was in her care when he was killed. And that's a hard hurdle to climb."*

While Mother and Father were traveling back and forth between home and hospital, Brother 2 was doing his utmost to protect them by *"trying to parent us."* His natural rambunctiousness became even more so as he tried to distract Mother and Father from their pain, exhausting himself in the process. Mother and Father were unable to aid him, in part in because of their own shock and lack of energy. Fortunately, his caring teacher provided a space at school for him to have permission to act through some of his pain. She tolerated his rambunctiousness and when it became too much, she helped him to control it. For a long time, Brother 2 refused to talk about Ben, perhaps in the belief that to do so would only cause more pain for his parents. Father says, *"He didn't want to cry and he didn't want to talk . . . .He was so worried about not causing us any more [pain]."*

Even Brother 1 noticed the difference in Brother 2's behavior when he returned home. Brother 1 says, *"I know he's been different now. Like he's always trying to get people, with my parents, "Okay. I'm here. I want to help you,"* kind of thing.

Brother 2 also helped his big brother *"all the time"* with the tasks he was still unable to do for himself. Once the family reunited and Mother and Father were able to lead the way in telling 'Ben stories' and visiting the cemetery regularly, Brother 2 was able to give up his role as parent protector. *"He's come out of that. He talks about Ben on a regular basis now."*

After three months, Brother 1 was discharged from the hospital and the family began their hard work of restructuring themselves--reorganizing their routines, reorganizing their norms, creating space for their grief as a family and as individuals. Brother 1 also worked to protect his parents but in a different manner from Brother 2's distraction efforts. He felt that his parents needed space to deal with their grief without the burden of worrying about their sons. He states, *"It's not really: leave them alone. It's kinda they're going through their own problems. And it's just they can handle a little bit of your stuff, but they're also going through their own stuff as well. So I kind of leave them* *alone."* Brother 1 further talks about his struggle to adjust to the absence of Ben, *"It was hard. I was not really aware of it. When I was in the hospital, I had no idea of it. So, it was good in that sort of sense. But I was still wishing it was not real, that he would just come back. [And then in February] It just seemed to [be] more a reality like, instead of wishing things would happen. And I knew what was going to happen; and it actually did. And that it was happening and so I had to face reality."*

Just as Brother 1 reports that his process of mourning the reality of Ben's death began some months after his return home, the process had been delayed for the rest of the family, as well, when they had been apart. Mother describes the feelings of shock, disbelief, and intense sorrow, that were put on hold during the family's separation, and hence, still continue ten months later. *"I'll be out working out in the garden or sleeping or whatever. All of a sudden, you panic because you realize, sure the day-to-day activities are somewhat the same, but then you just all of a sudden realize he's not going to get off the school bus and walk down the driveway. Or he's not going to walk around the corner and. . .to begin with, it was, I think it was so hard, because there was so many. . . .It's a panic shock. . . .It's like a bolt of it's true. But I don't know; your mind just drifts into, (sighs) some sort of, I guess, normalcy. . . .Last year we were digging in the garden, in our flower bed, and then all of a sudden, it's like a real jolt."* Father adds, *"I do believe that us being separated for as long as we were, traveling back and forth, and it definitely has prolonged a lot of those things. And like I said it's; I don't want to say that when we were all finally able to come home and be together, that it was like Ben's death all over again, because it wasn't. I mean, you know, but it was like, 'Okay, we can start the process, re-start the process again.' . . . I think it was a month, maybe, maybe 6 weeks ago where, because Brother #1 did not attend the Funeral, because he was in the hospital. . . .There was a DVD, like a Power Point presentation. He finally asked to watch that about 6 weeks ago, and that's the first time, you know. . . .He's seen anything about that; it's the first time. We asked him if he would like to see it beforehand and it was always no, up until about 6 weeks ago."* The family has in the last 2 months started to tell 'Ben stories'.

Their home has become a quiet place as the family struggles to figure out how they will go on. They no longer eat together at the kitchen table for a family dinner, but instead fill their plates and go to the living room where they watch TV—something that never would have been permitted before Ben's death. This also means that they are not having the usual discussions around the dinner table about the unfolding of their day.

Where once Mother and Father knew every detail of the boys' lives, they are now aware that there are gaps in this knowledge due to this change of routine and norm. Other household routines changed as well. Mother states, *"I'd say the day to day activities are somewhat the same. . . .You do the chores outside. I don't want to go through drawers or cupboards or, and I'm almost avoiding that kind of stuff. I mean [sighs] you still need to eat. . . .You still need to wear clean clothes. . . .They have to be done. It's not; like I have to push myself, but. . .you do them . . . .Dealing with Ben's brothers has been different. Keeping in touch with their teachers, making sure how they're doing stuff that needs to get done. [We] just live in this house and do the same things that we used to do. . . . There are times where I don't want to be here any more, in this place. . . .I mean maybe it's because the memories are painful. . . But, at the same time, I don't want to leave. But his room is the same. . . .I'd like him to come out of the door. . . .But it's painful. . . .But yet I think this is where Ben is. . . .I don't want to leave. . . .So, a lot of confusion. . . .There's just so much to process at once."* Mother knows that life "has changed" and has a sense that it will never be the same again *"I think about how things are going to be. I haven't come up with any conclusions yet. . . .And that's frightening."*

The family has not done the fun activities, the camping and fishing, they did in previous summers. Now their main time together is spent visiting the cemetery each Sunday where they can maintain a feeling of closeness with Ben. *"The things we do together now to involve Ben in our lives still are, you know trips to the cemetery. . . talking about, 'Do you remember when we did this?"* These trips to the cemetery are difficult, but helpful as well. As Brother 1 describes in his thoughts, *"It's something that has to be done and you have to do it. I do like going there."*

Many things have changed for the family in this year of 'firsts'. Their time is no longer filled with family celebrations of Christmas, Easter, and birthdays. Normally they would go to Grandmother's house for dinner, their break with her meant that Christmas dinner was at a cousin's house. There was no enthusiasm for decorating the tree, but eventually it got done, and a special ornament in remembrance of Ben was placed on the tree; it still hangs at the window. There were presents and stockings hung, including Ben's, but there was no real joy in the occasion. On Easter, where normally the boys would exuberantly take part in a treasure hunt, there was no hunt. In May, all three boys celebrate their birthdays. This year there was a quiet dinner for both boys where Aunt and Uncle joined the family for the meal and cake, but there were no parties with friends. Ben's birthday was celebrated with the building of his garden in the yard and with a trip to the cemetery, where a number of additional family members joined them to place flowers on his grave.

It seems that this quietness is creating a space for the family to come to an understanding of what their family is now, and what they are going to be as they go into the future. Father and Mother oftentimes sit out on the bench in Ben's memorial garden and have coffee together. Mother states, *"It's comforting. . . .Ben used to play there. The boys used to play there all the time. . . .'I'm just trying to listen for the laughter' but so far it 'has not appeared."* Father adds, *"You know, we have a little spot over here where we planted a few trees and we have a little bench that we sit on in the mornings or in the evenings. And we have a cup of coffee here, or whatever, and we just sit. . .and hold each other's hand and talk a little bit about. . .stuff. . . .The little spot out there that, on Ben's birthday, we built that. It's just some things that different people had given us, from, oh, little plaques to, a little angel and a little boy and a sun. There's not much yet, but when the trees get to where they should be and they blossom like they should, it will be quite nice. I mean it will be. We planted trees that do that [flower] in May. . .like we planted a white lilac. There are some flowering almond and things like that there. . . .I found planting trees strangely—I don't want to say, I guess I would say settling. Not comforting, because I get no comfort from planting them, but it settles me."*

Father contrasts this with his feelings at the cemetery, *"Sitting there, being at the cemetery is torturous, in a way, because he is right, his body is there. . . .You know my father's tombstone is two over. . . .My sister put it to me best that I could; she said, 'I can't.' She goes to the cemetery but she doesn't like it. . . .She said, 'I don't want to think of him as there.' . . .And that kind of made sense to me, in a way, that I'd rather think of him as here, than there."*

Father tells that he found it difficult to share his grief with others. *"Some subjects should be just between a man and his wife."* He speaks mainly to Mother, believing that, *"But at times. . .That was hard though, because I would talk about my grief and then it would make her sad, and then I was. And, we rarely were we both at the same place . . . rarely was there a day that we were both sitting in the corner crying. That didn't happen very often. . . .I mean we are very similar in a lot of ways, like we both are, I don't know, both very mindful of each other. But at the same point (pause) I don't want to say that, because neither one of us will push the other. Like if I'm at sorrow, I wouldn't want to force her from being sad to being mad. You know? But yet when I see her sad, it* *sometimes it makes me mad. Sometimes it makes me sad, and not mad at her, but mad because we have to be there. . .that we have to deal with it."*

The sights of the accident linger on for the family. Father has found that, *"I don't sleep like I used to. If I get 5 hours of sleep, I'm really lucky. It used to be about 7 hours was a regular sleep for me. . . . I don't any more, but the nightmares have gotten less frequent. But the sleep patterns of everybody in this house are different than they used to be."* He adds that this is a problem, too, for Brother 1.*"[He] is 15 years old; he's been in his own room downstairs for 5 years. He comes upstairs. There's a bed not right next to him, but beside his. He'll come upstairs at 11:30 or 12 o'clock at night, asking me if I'd come and lay in that bed down there. . . .The reason I know he's having nightmares or he can't fall asleep [is] because he's seen [he's] just seen your lifeless [brother's] body."*

As well, the family realized that the accident had created a fear of being in a vehicle for all its members. Mother, who had once driven school bus, now feels too afraid to do so. Father earned a great deal of the family's income truck driving through the fall and winter. He found that while he has always been a cautious driver, he became more so, worrying about the other driver to the point of distraction. He also found that the quiet activity of truck driving created too much time for thoughts of Ben and distracted him to the point where he would end up in places he did not intend to be, forgetting turns and wondering how he got there. The boys were afraid to travel in the small family car and, while it was a financial burden, Mother and Father decided that to care for their sons, they needed to provide a bigger vehicle, one in which they would feel safe.

Another delay in their grieving has been the trial of the driver responsible for the accident. As is often the case, legal proceedings necessitate holding on to the anger that arises during bereavement. Father acknowledges that his anger has been intense. In speaking of the trial which just recently took place, Father recalls his feelings at the time of the accident and where they are now. He states, *"I guess, at first, it was just a feeling it can't be, just the shock, and I couldn't believe it. This just can't be. And I know that's odd because, I mean, I was painfully aware that Ben was gone when I saw what . . . that part of it. And then, just the anger. . .I mean, and then I had some pretty. . .after that, just the absolute disbelief, after that again. . .the initial was jut the shock, just the terror . . .of seeing what we'd seen and then disbelief, I guess, was next, that it can't be. . . . Anger was a while after, and I don't know how long to say, but. . . .And it wasn't at any one, certain person, at that point in time. It was just, of course, I mean at him [the driver of the other car], but it was at everything after that. It was at God; it was at*

Grandmother; it was at. . . .There was no real place to focus my anger. . . .I guess that didn't really come until the day of the trial where, I can look, see him, say things to him. . . .It really helped it. Instead of shooting with a shotgun, I was shooting with it. And I don't know if, I guess it was because before, the anger really shot out and there was a whole bunch of little BB's going everywhere. . . .But then, it was at least one focus thing that I could be angry at then. But his experience with the criminal justice system has left him disillusioned. Although the driver was found guilty, sentencing has not yet occurred, and Father holds little hope that justice will be done. He adds, *"Victims have no rights. Criminals have every right in the world. The only sentence fitting for me is, well . . . there's only one thing he deserves. And it should have happened that day. . . .He should have died, not Ben."*

Father reports, however, that he experienced an unexpected avenue of support in a kindness act from a bond with people from the support group the couple attends. He reports, *"You have a bond with those people . . .the one couple came to court that one day, and you could have knocked me over with a feather, to turn around and see them in the courtroom there. . . .I might say that when the group ends, I hope those bonds don't end. And I don't think they ever will."* This support holds particular meaning because understanding from others, including extended family, has not always been present to the same level. He recalls, *"To be honest, I've had people tell me, 'I don't know how you did it. I'd have just beaten him to death right there.' Well that's, you have other things on your mind [at the accident scene]. I didn't even; I wasn't even looking for him, not at all. And that's where again, in my statement earlier, when you could tell somebody something, I guess I would have had to add, "Don't be afraid, to be where you're at, or be where you are at. Don't let others tell you where you are to be and don't let what other people say about what they would have done or where they are at, make you feel that where you are at or what you did was wrong. . . .Because nobody knows what they would have done unless they were there. . . .And that's (sighs) a painful thing to have to learn. . . .When you hear people say things like that, when they don't have a clue.*

As the first year of grief in Ben's loss comes to a close, time has allowed the Damant family to confront the changes in family routines. But as time goes on, Father has had space to reflect on the grief process but so far it has afforded him little peace. He states that being *"the reflective farmer that I am,"* he has been plagued by guilt and questions like, *"Why didn't I do more with my son? Why did I ever give him heck for this?*

Again, you know, what if? And of course, like you always go through that, I guess. You know, it doesn't matter if your child died of cancer or of something like this, you always, it doesn't matter what you did, it's never enough. . . .So I carry that. I should have done more, should have told him, I guess I could have told him I loved him every day of the week, which I think we basically did, but you always wonder did he know the day that he died that I loved him? I know he did, but that doesn't stop the question popping up in your mind. . . .I would say they're less frequent. I don't think they're any less powerful. They're just a little less frequent. . . .I would go through those things every hour of every day before with that. . . .I mean months ago it was constant. Now it's every day. Like it's a couple, two, three times a day, but it's not constant any longer. . . .The first 3 days, like the very first 3 days, I mean it was just, I mean it was all, everything was there, I mean absolutely everything. Everything was so powerful. . .so strong. And then it was okay. Brother 1 was going to live. Now we have this."

Although some changes have begun on a level of the practicalities of life, the family now acutely feels the huge hole left by Ben more intensely. They struggle to find ways to fill the gaps in carrying out the family chores that he so cheerfully and efficiently provided in the running of the household. His brothers grieve and miss him intensely. They are indeed, as Margaret Trudeau so beautifully suggests, that families must: *"Mass your memories . . .get them firm within you . . .and celebrate the life" (Curtin, 2001).*

Father suggests that recognizing Ben's spirit and who he was and still is in their family helps him to accept the reality. They are working to create Ben's spirit an ongoing place in their family. Father states,"I don't think anything that is in me could ever make sense of what this has [been], or what this is. There is no sense to it." Father explains that Ben continues to hold a place in the Damant family. *"Just in the fact that he's, I know he's not physically here, but he is here. In a way, it's almost like we all have family members that are gone to live thousands of miles away. We don't talk to them every day. . .but they're still there. They're still family. . . .You know he's just where we haven't gotten to yet."* Theirs is a remarkable story of courage in the face of overwhelming tragedy. One in which family members struggle to restructure their family at a time when there are still so many questions remaining. As Brother 1 explains, *"Those are still the same [the questions]. No answers. Ah, it really sucks. Like, it sucks. And, your life changes. [And it seems it will never get better.] . . . . It just really sucks."*

"(We) came in as a unit and left as a unit"

Family Grief and Mourning:

The Story of the Anderson Family

The story of the Anderson family relates the intense work of family support and the importance of telling Ty's story and creating his spirit. As Mother and Grandmother speak together during the family interview, they frequently complete each other's sentences and add to each other's thoughts. Together, they relate the story of the events that led up to the death of Ty and how, as a family, they have worked to remember him.

This is the story of a nuclear family who has been formed by events following another death--that of Carmen, the infant daughter of Grandmother and Grandfather and sister of Mother. It appeared in both the individual and family interviews that Grandmother needed me to understand that the death of a child requires remembering and support. Perhaps this has resulted from the dismissal she has felt from her own parents following the death of her daughter so many years ago. As a result, the stories told in the interviews reflect a firm base of support that exists for family members. Mother resides in her parent's home in large part because they understand that during illness, and following death when support is present in the family unit, members can work together to achieve essential tasks of survival. This essential value of support is also seen when Grandmother and Mother relate how Aunt is supported in the rearing of her children by Grandmother and Grandfather's daily, ongoing care of Aunt's two oldest children.

In both the family and individual interviews, Mother and Grandmother speak of Ty's ongoing presence in their lives. They speak of the many activities of remembering that they do as a family and as individuals. In the family interview, Mother and Grandmother relate stories about the "*sweet little boy*" who was always eager to be part of family activities. They tell how his presence has been seen and felt within their family. Their shared spiritual beliefs help them to construct his spirit and his ongoing place in their family while they work together to construct meaning in his short life and death. They use rituals of remembrance on a frequent basis during their daily life with his brother and cousins, as well as on special occasions, inviting others such as Ty's paternal grandparents and school community to remember him.

During individual interviews, both Mother and Grandmother related the private aspects of their grief-- the deep pain-- and mourning, including their willingness to endure at times in order to be of support during the expressed suffering of other family members. This is a family where Grandfather plays an extremely important and active part in the support given to family members. While Grandmother and Mother believed that he would be willing to take part in the interviews, when the time came he felt unprepared to do so stating that he could not speak openly of his pain at this time. Perhaps the role expectations of grandfather as protector required him to maintain enduring and participation in the interviews could not allow him to maintain these tasks. Further exploration, in another study, of the societal expectations of the Grandfather role could help us to better understand this important component of family work during bereavement.

Telling the Story: The Spirit of Ty

When Mother and Grandmother speak of Ty in the family interview, it becomes apparent that speaking of Ty is a daily occurrence and is as natural now as it was when he was alive. Grandmother says, *"Well, I just always did everything with him, so it's like choosing the juice, or choosing the food".* Mother adds, *"We talk about him. Like it's not always talking about him and crying. And it's like. . .happy".* Grandmother confirms, *"I talk to him [Ty] all day and everywhere I go. Grocery Store. . .car. . .all day. I talk to him all day. . . . He's inside me".*

The cousins are frequently overheard telling 'Ty stories', including him in their play and writing letters to him. These stories incorporate a continuing presence of Ty in the Anderson family. The cousins have reported feeling his presence and seeing him. Cousin 2 reported that she frequently saw Ty at school and Cousin 1 described that one day she saw him as *"a glowing white with a necklace, diamond—crystal necklace . . . describe[ing] exactly how she felt he looked, so matter-of-fact."* Both Mother and Grandmother believe, *"He's not gone. . . .(GM) I feel him on my lap and I feel him on my leg . . . (M) I can still feel him".*

But telling the stories of Ty also includes remembering the painful memories of his illness and suffering. *"He was born with a fetal heart problem. . . . a pretty complex condition. . . . he was never going to be fine. . . .he didn't have any surgery till he was almost four. And then he had his first surgery and did really well. And then he had his second. . .two and a half years later, and it just didn't go as planned. He still lived for 6 months after surgery, and got on the list for heart transplant. . . .we were waiting at home for a heart. And then he just ended up kinda getting sicker and sicker by the week. And we ended up in the hospital, and he was doing really well. We were just waiting for a* *heart. . .all of a sudden, he had a stroke. And it was so unexpected. [Grandmother adds] he suffered so much that last week".*

Together with these family stories of Ty, this young mother is busy gathering her own personal remembrances of a son who so changed her life. *"I spend time in Ty's room and I allow myself to grieve. . . . If I miss him . . . I'll go to his room and I'll look through his stuff. I spend a lot of time at the cemetery. I do a lot with pictures. I have lots of pictures, photo albums. . . . And I know that I'm going to cry, but I don't think there's anything wrong with that. . . . I deal [with it] in my own ways".* His spirit lives in his family, *"He was so sweet. He was very mellow and kind and. . . . very charming. Yeah, he was a sweetheart".*

The Family

The Andersons are a family that has experienced the death of a child in two generations. Family norms, as well as societal expectations, have influenced the way the family worked together to create space for mourning. Recently, the family experienced the death of Ty, who was born with the same congenital heart condition that had 30 years earlier taken the life of his Aunt Carmen. Grandmother recalls that when Ty was dying, *"I thought, "God won't take two of them, will he?" . . .God didn't do that. Well, He didn't, but He did, I guess. . . .We had 7 years with this one. . . .That helps. We didn't have any years with the other one. It makes grief worse. . . .And it's just so unfair to lose two".* However, she explains how there is never a "right time" to lose a child, *"Oh, with Ty it was, we had time to get to know him. And he was in pain. My daughter [Ty's aunt] just went peacefully. He shouldn't have to go through all that torture. . . .Ty went through more than any child should have to go through, EVER. . . .His aunt didn't have to go through that".*

Over Ty's seven years of life he had undergone four surgical procedures that were not available to children when Aunt Carmen was born; she survived only two days. Grandmother and Grandfather were a newly married couple when Carmen was born. They were influenced by extended family members and told to "*put your grief in a box and put it in your pocket.*" At that time hospitals did not take pictures of children who were ill and dying as they do today, so the family has no visual reminders of their daughter. They were discouraged from having a funeral, but the young couple decided that they needed to mark Carmen's existence. Consequently, they had a small private service and buried their daughter and have worked to remember her. They created a permanent memorial at the cemetery where over the years they, together with their two surviving daughters, remember Carmen. Grandmother still "*vividly remembers how she [I] felt*." Within the year, she was pregnant again and "never had time" to grieve. She recognizes the deep grief she feels today is not only in response to Ty's loss, but it is also grief for the loss of Carmen. Grandmother tells: *"I think people think that losing a baby is not such a huge thing. You can just go and have another one. And that's not fair, either. So I think maybe not grieving that death, made Ty's harder. . . .When life isn't acknowledged as such, and as being just as important as any other life, [it is difficult to openly grieve]".*

While societal norms of the time dictated a silent mourning when infants died, the young couple acknowledged Carmen's life and spoke, often through their tears, of her among themselves over the years. Later, they made sure that their two daughters, who followed,, knew that they had had a sister. One of Carmen's great-grandmothers would in her old age, talk about Carmen, "*She was so cute, that girl with a blue eyes.*" This gave Grandmother the only permission she received to grieve. The experience of Carmen's death influenced the family's bereavement following the death of Ty.

At the time of Ty's birth, Mother was very young and Father was unprepared to handle the responsibilities of being a parent. In fact, he denied his fatherhood and required paternity tests to have him acknowledge it. However, even when it was confirmed that Ty was his son, Father was unwilling to take on the responsibility of fatherhood and had very little to do with Ty throughout his life. Ty's heart condition was evident immediately at his birth and Grandmother acknowledged that Mother and son would require the support that independent living could not bring. Hence, they came to live in Grandmother and Grandfather's home. Grandmother reports, "*Ty needed to be here.*" Over his seven years of life, Ty *was "just always attached"* to Grandmother and Grandfather. While Mother took the lead in his parenting, Grandmother and Grandfather were also instrumental in providing emotional, as well as financial support, to Mother and Ty. When hospitalization was needed, Grandmother suggests, we would "*come in as a unit and left is a unit.*" However, Father was never present for the surgeries or at the bedside during recovery. Father's parents started to take an active role as Ty's grandparents when he was about three years old. At that time, they began monthly overnight visits and occasionally Father would visit, allowing Ty to know him as Father, but never as 'Daddy'. It is Grandfather who took on this active role as daddy; Mother says, "*My dad was like his dad.*"

When Ty was about four years old, Mother formed a relationship with Stepfather. After the birth of Brother, Mother and Ty moved out of Grandmother and Grandfather's to form a new family. But this was not successful. Mother was not accepted by Stepfather's family and was rarely invited to their home, even on special holidays such as Christmas. As a result, most often Mother would take Ty and spend the holidays with her parents, while Stepfather and Brother would spend the holidays with his parents. *"We never celebrated, just the four of us, as a family".* As well, there was little support for Mother from Stepfather when Ty faced further surgery. Preparing for the last surgery and experiencing the conflict that can be part of a home where there is a sick child, Mother chose to leave Stepfather and to return to her parents' home a couple months before the scheduled surgery. Grandmother reports, *"Ty was sick. And the tensions were high. And we were back and forth to the hospital".*

But, Mother adds, *"He [Stepfather] never went to the hospital."* While Mother spent time at the hospital with Ty, Stepfather remained at home taking care of Brother. When Ty died after suffering a stroke while awaiting a heart transplant, Mother needed the presence of her young son in her bereavement, but Stepfather's care of Brother during Ty's lengthy illness set the stage where *"the tip in the power scales happened"* leaving Mother the added burden now of fighting a custody battle with Stepfather over Brother. While Brother spends half his time with Mother and the other half with Stepfather, Mother realizes that she would like to have her young son with her more often. His presence not only distracts her from her grief, but gives her the hope that life will carry on; both things she desperately needs in this first year of bereavement. Mother relates that most of the time she can care for Brother (she has joint custody of him), but some days are still difficult. She says, *"Most days, it's better [than at first following Ty's death]. I still have days where it's hard, but there's never been a day that I haven't done it that I've had him. I mean, I have to, right, for him? . . .you just do it, but there's days where I feel happy and we laugh and we play. And there's also days where I'm sad and we don't laugh as much. . . .And we might not go to the park. But the last couple months, it's actually been better in forming a relationship with him and actually being able to feel some joy again. That's probably just come back in the last, probably, three months, now. . . . It's a different kind of joy. It's not joy like. . .I think it's more, it's mild. You're happy, but I think that overall, like before you'd feel joy; you'd feel happy. But now, there's an underlying sadness. . . . Like even if you're laughing and smiling, it would be one second later that something, memory triggers back, and you're just sad again. . . . So it's not a* *very long-lasting feeling, for sure."* However, Stepfather is not able to understand this and, instead, fights for every extra hour she would like to spend with Brother, *"He's feeling like he's losing control. So that's why it's been such a big fight for us".* Grandmother tries to stay at a distance in this fight, but acknowledges that further pain is brought about by the conflict.

Mother reports that her days are *"pretty routine. . . .Like days that I have Brother and I don't work, we'll go to the park and for walks and stuff. And my parents come home, usually, from work in the evening and have dinner. And, it's pretty standard, routine-wise here."* But she recognizes there is a different feeling in the house and, *"I think there always will be. . . .But I mean, you can't go through something like this and expect that anything's going to be remotely the same. And I think we've all accepted that. We have a loss and we live with it. . . . But nobody expects anybody to bounce back, here. . . . So, I think we all respect that the other person's grieving".*

Life in the household has changed—it is quiet. Their home was once always a "party place" with the family celebrating every occasion--Christmas, Easter, Thanksgiving, birthdays, and even un-birthdays in a big way. Mother led the way in planning the parties along with Cousin 1. Grandmother carried out the plans, and Grandfather cleaned up. Now, it is only busy when grandchildren are present.

At Christmas, Ty still has a stocking and presents. Last Christmas his presents were 16 videos *"for the family to watch with him, as a unit, so, inclusive."* This norm of working together for this "*strong family unit*" laid the foundation for their work together as a family in mourning for the loss of Ty. His brother and cousins often play with the many toys that remain in his room. Mother has a rule that while the children are free to play with Ty's things; these things must remain in his room where they cannot be lost among the many other toys in the house. However, no one is allowed to play with his Play Station, a particular favorite of Ty's. Grandmother tells a particularly heartwarming remembrance story when she describes the trip Grandfather took with cousin 1 and 2 to the lake recently. Ty was given a remote-controlled boat by his paternal grandparents, but was never able to take it to the water himself before he died. Cousin 1 and 2 took the boat this year, *"And they are going to sail [do] that at the Shushwap . . .with him. . .and that's what we want them to remember, too, and sort of how connected [they are] to Ty. That is how our family is".* As well, *"the girls will watch his videos . . . all the time."* While mother frequently looks at photographs and watches the slides prepared for the funeral, she finds she can *"not [watch] an actual live video. . . .[In the photos] you are not hearing him"*.

Mother's bereavement support comes primarily from Grandmother and Grandfather. While Mother's sister, Aunt, is present in the household a great deal, (the oldest two of her four children live there during the week when school is in session) Aunt's lifestyle creates a distance between them. As well, Mother finds that her friends cannot understand the depth of her pain. Being in their mid-20s, their lives often do not involve parenting, much less the experience of death, not that of an adult and certainly not a child. Mother finds it difficult to speak of trivial things and to feel empathetic with friends who are going through minor difficulties, especially those she considers self-inflicted ones like mild eating disorders. As a result, her life is focused on her remaining child, her part-time work, and life in her parents' household. She realizes, for now, she is better off living in her parents' home, *"I don't think I'd be able to do it. . . . Maybe, maybe in the near future, I might, but not for the last year."* Mother states, *"My whole outlook on life is different. And my relationships with a lot of people; I find I'm only close with a handful of people now. Whereas I used to have a lot of friends and a lot of people I talked to. I was really social before. . . .And now I find myself more, a bit more closed off and just concentrating on a small amount of relationships, instead of a larger amount of relationships that don't mean as much to me. I think it's actually gotten smaller, my group of people, in the last year, for sure"*.

The family has always had a norm of open communication. They are a family that says what's on their minds, often disagreeing with each other and nattering at one another. Grandfather is the *"natter king*" but no one takes this too seriously, for they know that he is always there for them. *"He can make sure his family is all right and then go to work. . . .He's been very steady. . .quite the rock"*. It is this strong foundation that allows Mother to create a space for her grief. Mother and Grandmother complete each other's sentences as they explain, *"[Mother] There's pieces of bad days every day . . . [Grandmother] there's not a day that there is not some sadness . . .[Mother] and there's a point in everyday where somebody's crying, or quiet, or withdrawn, or nattering at each other . . .[Grandmother] um,um. . .[Mother] and you know, it's stressful"*. But, *"We're just kind of letting each other do it, maybe there's a pat, or there's an acknowledgment, or sometime just a look. Sometimes, you just leave them alone."*

As previously seen, the family has norms of support for one another, including moving home or caring for grandchildren in the home. Where there are rules for the behaviors of children in the house, grandmother states, *"I don't try to police adult children. Mother came home because of his [Ty's] tests, and Ty was going to go for surgery, and because we have a big house, and because Ty needed to be here".* As a result of this family norm, the loss of her relationship with stepfather and of the home where she lived with him, *"is not a very big loss. We were already separated anyways before, so it's not like we were doing well. . . .He wasn't there for me".* But for Mother, her parents "*always are [there for me]."* The home is also open to Ty's paternal grandparents, who are often present for important celebrations such as his birthday and part of Christmas day.

While today's society may be more open, in general, to acknowledge the loss of a child, Grandmother experienced a similar reaction from members of her extended family, especially her mother, when Ty died as when Carmen died many years before. Although they attended the funeral, traveling some distance, and were helpful in many ways, Grandmother reports, "*It was really odd. I don't really want to slam my parents, or anything but it's almost like they were afraid of me....They wouldn't sit with the family at the Funeral. They sat in their own pew, like they thought, it's not like a grief they wanted to share. They didn't want to be part of it".*

These great-grandparents, and siblings have not called since to inquire about how the family is doing in their bereavement. When Grandmother speaks to great-grandmother by phone, it is as if the family has not lost another child-- there is no mention of him or inquiry as to how the family is managing. Grandmother felt strongly after six months that she was no longer to speak of Ty to Great-grandmother and that once again she should simply "*put my grief in a box and put it in my pocket."* However, she has chosen to reject this advice and encourages Mother to openly mourn. The Anderson family actively mourns the loss of Ty. Another great-grandparent has helped to lead the way. Grandfather's father has been very helpful. Grandmother reports, *"He was devastated, actually, because he had just lost his wife. So, it was right. So, actually, he has been pretty good. [Calling] every day. Grandfather talks to his dad every day".*

As the family approaches the anniversary of Ty's death, his paternal grandparents will be present to help build a memorial garden in the backyard-- a soothing place which began in the spring when the family poured new concrete for a deck and wrote in it, "*Ty lives here.*" And indeed he does, in his many photographs prominently displayed, in his name together with his cousins on the mailbox, in his room still as he left it-- with his many toys and clothes in the closet. But more importantly, "*He is still part of the unit*" in the stories the family tells on a daily basis. Brother, who was only 18 months old when Ty died, has come to know him through his cousins, who Grandmother describes when they were with Ty being "*like bugs in a rug.*"

In this first year since Ty's death, the strong family norm to care for each other is evident. Taking care of others is how Grandmother copes, she reports, *"Well, I work a full-time job. And I help raise two of my grandchildren. And Brother is here half-time and. . . .I guess we bury ourselves in the kids.* Work and "*to be an example to Mother*" is what keeps Grandmother going. She adds, *"What's going to happen to her if I don't. . . .What happens to my husband? What happens to my kids? What happens to my grandchildren if I don't cope?"* She keeps going in spite of the pain and struggle because, *"They're worth it to me....Life has to go on".* She believes Grandfather is also working to be strong for her. She reports that it helps a great deal, *"He's my inspiration. . . . He's the nicest person I've ever met. . . . He's my anchor. And I think that if he can do it, I have to be able to do it. And so, we hold each other up. We always have. . . . I owe that to him. . . . There's been times I just want to run away and hide. . . . But, I wouldn't do that to him".*

In spite of their willingness to care for each other, the personal side of grief is apparent at times. When asked to tell what it was like for her to experience the loss of Ty, Grandmother wept. She reports, *"This is a bad week. . . .It's coming up to the anniversary.*" But even when asked if she wanted to postpone the interview, she did not. She reports, *"I think that what happens now, this week especially, is you re-trace the dates. . . .What happened every day. [struggles for control]. . . .I mean he suffered so much that last week. . . .And it's hard to cope. . . .So, what was it like? It was the worst thing you can imagine for a mother. . . .I'm still in shock. . . .And, time doesn't make it any, any better."* Further, Grandmother speaks of the hard work of coping with grief by keeping busy with family and admits how, on days when the house is quiet and she feels no responsibility, she sees other, easier ways to mourn. She says, *"I'm all by myself and I love it. . . .Well, after Ty passed away, he [Grandfather] went to the lake for 10 days with the kids, so I was by myself for that time and. . . .I quite like it myself, my time with myself . . . .I do find some peace, being alone. . . .If I could [pause] go away and be quiet forever, I probably would. . . . I'm sure I would. I would choose that as an easy out. . . .But that's not why I'm here. . . . But to be brutally honest, I'd love to go away and just* *think. . . .I think right now I live for my kids and my husband".* Mother adds, *"We cry sometimes together and at the same time, but it's a real personal thing to me. And it's still pretty, pretty heart-wrenching for me. . . .I like "just to be on my own sometimes. . . .I talk; I'm not a huge talker. . . .I don't reach out and talk to people and talk to my parents and my friends and my family. I'm just, I'm not like that. . . .I'm not a huge fan of grieving with people."*

While the family recognizes that *"grief is forever"* and that their suffering has only begun, they take courage in the knowledge that they are 'giving back' through the creation of a foundation in Ty's name. Grandmother says, *"We're trying hard to kick off the Foundation."* They are creating a legacy that is fitting of this small boy who, although he lived such a short time, gave so much to their family.

"*Because my son was so much more than his death and his illness*"
Creating the Spirit of the Child:
The Story of the Myhre Family

The story of the Myhre's family bereavement is told by Mother, Sister, and Grandmother. In this family it is permissible to hold different views on the definition of family and the roles family members play. While Mother firmly holds with the view that only those who played an active role in Ray's life should be considered "family"--including stepfather but excluding father and his family, Sister and Grandmother disagree. This is seen in the interviews when Mother relates her opinion that Ray's father and family had no role to play while he was dying or at his funeral. Grandmother disagrees that despite his own personal problems, Ray's father loved him. It was important that he, and his family, were present during Ray's illness and funeral. As well, Sister expresses her views that, while stepfather was enormously helpful in providing care to Ray during his dying, his place as a family member has not yet been established due to the limited length of time he and mother have lived together (two years). Despite these differing views, this is a family where support of one another is more important than individual views and at times even needs. In their individual interviews, all three women relate how their own individual needs at times took a backseat to their need to be present for other family members. Their kindness and loving acts toward one another and, other family members, are present in abundance. While Brother struggles with his own difficulties, the women relate how they incorporate him into this family work during bereavement, making allowances for his need to stand at a distance from his pain.

The Myhre family actively works together to incorporate Ray's spirit into their family. This is seen from the stories of their youngest member, Niece, who shares her stories of seeing her "fairy" Uncle to their oldest member, Grandfather, who continues Ray's habit of collecting rocks at the seashore, placing them beside his picture as a constant reminder of Ray's presence in their family. Mother and Sister relate in the family interview their many efforts to create symbols of Ray in their family, to speak daily of him, and to keep his memory active in their family traditions.

While in the family unit as defined in these interviews support and working together is apparent, it is also clear that family definition guides this research. Ray had other family whose story of bereavement was not told in these interviews because Mother, the family spokesperson, does not consider these blood relations family. This points out an important aspect of doing "family research"-- how we define family determines what we learn about a phenomenon. It would be very interesting to know how Ray's father has done the work of grief and mourning and if his experience has been one that incorporates family work.

Telling the Story: The Spirit of Ray

The spirit of Ray lives in the many dreams and visions of the young man who was *"an amazing kid. . .[who] loved Tai-Kwan-Do. . . .his friends [and] socializing. . . .his bike. . . .He was such an easy kid. I know his friends referred to him as 'the hub'. . . .Because Ray couldn't stand hurt feelings and he had all; everybody loved Ray. So he had friends from all spheres. And he was the center. And he'd bring friends from all different groups of kids together. And if kids were maybe having, as kids do, they'll have little fights or little tiffs or hurt feelings and that. Ray would always work it out so everybody was happy again."* He enjoyed school and was a *"seeker of knowledge"* who always had interesting questions about the things that he saw.

Mother has had numerous dreams of Ray that bring her comfort. *"I've had a number of instances where, where Ray has come to me. The first time was a few weeks after his death. There had been quite a lot of media attention. . . .And he appeared to me and he said to me, 'It's cool, Mom.' And then the next visit was like I was looking into a doorway into a room. And he was sitting at a table. And he wasn't looking at me. But he was sitting at this table with three very wise beings. And it was very comforting because I* *knew that he was getting his questions answered. And then, one of the times after that was, because I kept wondering, 'Will Ray be 13? Will he stay 13 until I come to the other side? Will he grow, what will he be like?' And so, with that, it was: we were separated by a fence, and I couldn't cross the fence. And I could see him in a distance with a group of young people. And I knew that he was okay. They were joking. I had this sense of them laughing. And then he came to a kind of an opening in the fence and standing behind him was a girl. And I just knew that that was sort of his spiritual partner. And in it he was grown. And I looked at him, my first words were, 'Oh, my God, Ray, look at how tall you've gotten. I can't believe how tall you are.' And it was like, 'Of course, you would look this way because this is what you would look like.' And then it was just and then he was gone. But I know I hugged him and he didn't say anything. But it was just very, very comforting. . . .I've also had lots of little signs from Ray. I know there was one time when he touched my hair. He's left me a little pewter stone on my pillow, when there's been nobody else in the house. And it was turned up to say, 'Love.' And often I'll ask him to, 'Ray, if you're with me today,' and I'll ask him to play a certain song or something by a certain band. And when that happens, it's when I get in my car and I turn my car and that song is there. . . . It's always when I turn my car on and start my car in the morning. And so those, I find those very comforting, very, very comforting.*

His spirit is also kept alive in the symbols the family uses as reminders. Mother and Sister tell a story that always brings a sense of Ray and gives them a good laugh. *"And there was an angel for Niece from Ray. . .And every year there'll be an angel. . . .And a fairy, because she always thought he was a fairy. She couldn't grasp the concept of angel, so . . .she told everybody her uncle was now a fairy. . . .It was just a number of hours after Ray had passed and Sister explained to her; she was very connected to her uncle and he loved her dearly. And she said, 'Your uncle is in heaven now. He couldn't get better here; he had to go to heaven. But he's an angel now. He's always going to watch you.' And so, a few hours later, she comes, 'Mom. My uncle's, he's a fairy.' And we could just hear Ray's voice, all of us, 'I'm not a fairy."* Through this first year living with the loss of Ray, their family sharing of Ray stories has brought comfort and a sense of Ray and of the meaning his life and death.

The Family

At the time of Ray's death, the family is exhausted, overwhelmed, and shocked. It took 2 1/2 months to obtain a diagnosis for his illness, Mother recalls: *"Ray was* *diagnosed with a very rare form of cancer. Ah, to date, in 35 years, there have been 8 documented cases in the world. And he was the youngest.[At first in emergency] they diagnosed him with pneumonia, because what they saw was the beginning of a solid tumor in his left lung. And it looked very much like pneumonia. . . .[And then] this "pneumonia" was getting worse. It was growing. And so, she started to try to get us in to see a specialist. . . .And it became very apparent that Ray was very sick. But we didn't dream; cancer never crossed our minds. . . .And she [the specialist] said, 'I'm so sorry to have to tell you this. We may be looking at a cancer.' And that was the first time it crossed my mind. And. . .my world ended."* It was only 10 weeks later that Ray died. During these 10 weeks, and particularly the last two that he spent at home, Ray was in a great deal of pain—a pain that was unrelenting and uncontrollable. Mother adds: *"They just had to keep broadening it out until they discovered, August 10th; he got his diagnosis that he had squamous cell lung cancer that had metastasized to his bones. And it was throughout all of his bones. And so he was, at that point, he really was palliative. It exploded in him. . . .And every day, he lost ground. He was diagnosed August 10th and he passed away October 30th. . . .His disease was very horrible because his pain, they couldn't get a handle on his pain."*

As this brave, gentle 13-year-old young man fought to survive, his close-knit family, Mother, Stepfather, Sister and her family, Brother, and grandparents sat by helplessly. Grandmother recalls: *"And we were so very helpless; because if any of us could have, we would have traded places with him because both his Grandfather and I, we've had wonderful lives. . . .And I've had a very, very full life. . . .I've got this healthy body, and I would have so gladly traded."* Mother adds, *"I had a lot of anticipatory grief before he passed away, knowing what was going to happen to him. Every time I looked at him, I knew I was going to lose him. And I still, because hope has always been critical to me and critical to Ray, so I never tried to lose sight of hope that maybe, just maybe he'd be that miracle if I just tried hard enough. . . .I would have battled the devil himself for my son."* She adds: *"The hardest things in my life were: On July 20th, I had to tell him that this might be cancer; on August 10th, I had to tell him it was cancer; on October 12th, I had to tell him there was nothing more they could do. And the very first thing he said to me, he grabbed me by my hands and he had beautiful blue eyes [mother getting teary and voice breaking]. He looked at me and he said, 'Mom. Promise me you'll be okay. Promise me, Mom, you'll go on.' But his concern was always. . .for everybody else to be okay."* Mother recalls her shock when Ray died: *"And then when Ray passed away,* *[pause] it was so painful. And sometimes, I can still see so clearly him taking that last breath. . . .And I didn't expect him to go. I just, I mean I knew it was coming, but I didn't think it was going to be that night. And, I'd been falling asleep. The kids had all been here. And when I look back, I can see that Ray was saying good-bye. . . .And we always told him how much we loved him. And that night, we were all sitting kind of in a circle around his bed and he would just open his eyes and he'd look at each person. And then he'd close his eyes and he'd rest. And then he'd go on to the next person and do the same thing. And I realize now he was saying good-bye. But I didn't pick up on that then."*

The family had always been close, Mother says: *"I'm so blessed to have such a wonderful family. We were there for each other. . . .I've always, my family has always been a source of strength for me. I'm very connected to my family. . . .We're very connected to one another. . . .I always worked really hard to try make us a strong family, so that I wanted to give my kids a sense of that, that we were a family and that we had roots and that we had traditions and that. . .And that we would stick together; and that I would always be there for my kids, no matter what."* And they drew closer together to care for Ray and then to support one another during bereavement. Mother adds: *"I mean we were close before. We stayed close during Ray's illness. We're close now. We're very supportive of one another. . . .I rely tremendously on Sister for a lot of support. We support one another, because with Sister one of the key things is we can talk about Ray; and it's not only about the sad things, but we can still remember and laugh together."* This closeness has brought about some changes in their lives. One is that Sister and Brother-in-law realize that their geographical distance for his work needs to change. Sister says: *"Lately it's been more on that he's out of town. He's home every 10 days or so. But since Ray's passing, it's a goal of ours for him to be. . . home. . . .And that will be happening shortly, very shortly."*

Mother took time off from her supportive workplace and was with him day and night while he remained in hospital, and then provided care at home in his final two weeks. *"I work in a very supportive environment. My work has been wonderfully supportive."* Sister, despite her other duties, was at the hospital daily to provide emotional support to Ray. Mother recalls: *"In those last two weeks – all through his illness in the hospital, because he really was in the hospital most of the time. . .they visited him every day. And same with when we were at home; he was surrounded by his family."* Sister had always been a loving presence in Ray's life, even though she was 14 years older. She says: *"But even when there's a 14 year. . .gap, between, Ray and I* *were very close, very close, especially because we lived together. . . .And because of his relationship with Brother-in-law and his relationship with Niece. . . .We were very, very close to him. We did a lot of family things together, not as far as trips and things like that, but a lot of just, general outings, whether it was to get ice cream, go see the Bright Lights at Christmas, things like that."* Mother shares a very poignant moment that encapsulates Sister and Ray's relationship: *"He would just ask Sister just to come lay with him. . . .And I don't, there's a song, I don't know if you've ever heard it. It's called "Chasing Cars". And it's got a couple of lines, 'If I lay here, if I just lay here, would you lay with me and just forget the world?' And that was Sister and Ray's song. And we've got pictures of the two of them laying together because he would lay and they would hold hands and talk."*

Sister's husband, Brother-in-law, had been in Ray's life for many years and was the one person, who even up to Ray's last days could bring a smile to his face. Sister describes her husband and his relationship with Ray this way: *"He's a beauty; he's a great guy. . . .It affected him as much as it did us. Because I've been with him, basically since Ray was a baby, and he'd always be around."* Mother adds, *"And it was wonderful because when Ray was SO sick, Brother-in-law would come in and he could say things and he could still make Ray smile."* Sister adds that his steady presence in her life has been particularly valuable in this crisis. She says: *"But, Brother-in-law's SO good at listening to me, like that's usually when I have my breakdowns is when I'm with him."* The young couple had moved across country when first married, but came back to live with Ray and Mother when Sister decided to go back to school. During Ray's illness and in their bereavement, Sister's role has been one of supporting other family members, often putting her own grief on hold. She says: *"I call Mom every night if she doesn't call. We talk every night on the phone. . . .And we can say, 'You know, I had a really crappy day."* Mother adds: *"Or, for example, I just, out of the blue, I was just crying. Sometimes it just hits you and it just levels you. . . .And we talk about Ray every time we're together. We talk, and like I say, we can also laugh and that's great."* As well, it is Sister who did a lot of the arrangements for the "Celebration of Life"—Ray's memorial service. Mother and Sister recall the event: Mother: *"I didn't have a funeral . . .I had a celebration of his life. . . .And it was beautiful"* Sister: *"There was lots of laughing."* Mother: *"Lots of laughing. I spoke. Very good friends, and they have four boys; and those four boys all participated. And, because the boys had asked; they really liked to play music and that. . . . And their mom was saying, 'They're not professional musicians.' But I said, 'I don't* *care if they play every note wrong. It's coming from their heart. And they're doing it for their friend.' We had a display. Sister did a beautiful display: pictures, mementos. . . . It was sad; but it wasn't. I don't know how to describe it."* As well, it was also Sister who brought home Ray's ashes: Mother: *"And Sister actually just brought his ashes home. I couldn't."* Sister: *"I got nominated to do all that part."* Mother: *"But then, in the last month or so, well, a little more than that, I said, 'I'm ready to bring his ashes home now."* Sister: *"And I actually brought it up with Mom, because I didn't like him being there. I didn't want him there."* Mother: *"And the day we did the cheque presentation at the [local children's hospital], Sister said, 'Mom, could we bring him home? I don't want him to be with strangers any more.' And I said, 'I feel the same way.' . . .And so, she did. She went back there. I heard this knock on my door; and there's a very tearful girl clutching her brother's urn in her arms. . . .And it felt right."*

Ray had forged a strong bond with Niece; a mutual relationship of delight was formed between this energetic little girl and her adoring uncle. When he was dying, Ray was afraid that Niece would forget him, a concern that became unfounded as this family worked hard to establish a continuing place for Ray in their family. Sister recalls: *"And his one fear was that Niece would forget him . . .And part of that, too, was we just wanted to keep him alive for her."* Mother adds: *"We look at pictures and we've got so many pictures where she's in the picture with Ray. . . .And she likes to look at them; she often is hauling out photo albums. And she talks, 'That's my uncle Ray,' . . .and so we talk about him and about things they did."* Niece continues to talk about him and feel him close by. Ladybugs have become their special symbol. Sister says: *"And we have a new thing with ladybugs. That's my and Niece's thing because one day Ray joked. We were talking about reincarnation and he said he was going to come back as a bug. . . .And in the middle of winter, Niece would find ladybugs. And so, now ladybugs are our, me and niece's, way of remembering him."*

Sister speaks of Ray to anyone who will listen including her coworkers and clients, *"My job is very therapeutic. I'm very close with a lot of my clients. Most of them know about Ray, either from me talking to them about it or it was so . . . publicized in the media and stuff. A lot of them learned through that. But I spend a lot of time talking to them and THAT, to me, is very therapeutic. I've a lot of support. It's a very small office; a lot of support from the people I work for and work WITH have been absolutely amazing."* She adds: *"I'm over here a lot more with Mom, especially now that she's by herself, and with Brother-in-law being out of town. We spend a lot more time together than we ever* *used to. . . . My day is consumed a lot with thinking of my brother. You know, it's an every hour of every day thing. . . . I'm very much a picture person. I keep a lot of pictures and stuff, of him, in my room and I talk about him with my clients. And so he's always a part of my day. . .but it's just trying to keep busy."*

In the two years before Ray's death, Mother formed a new relationship with Stepfather. Although they had been friends and coworkers for some years, Mother and Stepfather began living together and became trusted partners in Ray's care. Mother says: *"You know Stepfather is the most wonderful man I've ever met. And his kindness and compassion with my family, his caring for Ray, I couldn't have asked anybody to have loved Ray any more. . . .And cared for him any more. And how he looks after my family and loves my family. He'll do whatever he can for Brother, even if Brother can be off the wall sometimes, Stepfather will just, "It's okay."* During Ray's illness and particularly in his dying, Stepfather provided hands-on care to Ray, forging a deep bond that Ray described as one that was closer than with his long absent biological father.

Following Ray's death, Stepfather was overwhelmed with his grief and *"in a fog"* attempted suicide. His severe grief reaction led to a temporary difficulty in the relationship; Mother could not understand how someone could so willingly give up his life when Ray had worked so very hard to hold on to his. Mother says: *"We, I was angry. I was really angry. Sister was really angry."* Sister adds: *"There's still some harbored feelings on that one."* Mother continues: *"We talked about it and I said, 'I really feel suicide is very selfish.' So Stepfather has come; he's worked hard and he's come a long ways for that. And he's very remorseful that he did that act. . .and he apologized to my family. He apologized to my parents. He was just, like he said; he was like it wasn't even him. He said he was in such a fog; he doesn't even have much recollection of that time; so we had a lot of healing to do. . . .A lot of healing to do. But Stepfather is also an incredible man who I love dearly. And forever and ever, I will carry the picture of him with Ray. You know, cause Ray, it would take (sighs) so much. He was so weak, and the cancer, some of the tumors, pressed on his spine. And so he lost a lot of muscle function. And, to just to go to the bathroom, when he could still walk, you know, Stepfather would get him sitting up on the edge and then Ray would put his arms around Stepfather's neck and he'd just rest his head. And he'd close his eyes. Stepfather had his arms around Ray. . . .And he'd just say, 'Ray, I'll hold you till you're ready.' And I'll just carry that picture forever."* As Stepfather worked hard to rebuild his relationships within the family, Mother was able to forgive him for bringing more pain to the family when they were already in such deep pain in losing Ray. Mother says: *"And he loved Ray. He loves me. He loves my family. And he's a wonderful man. And he was just in such pain that I've forgiven him."* While Sister appreciates the role Stepfather took on within the family, she finds it difficult to feel as close to him as Mother does. For her, he has only been a member of the family for two years and she is still forging a bond with him, one that has been severely tested by his suicide attempt. She says: *"You know, I'm still pretty angry about it. We have a lot of rules that have been set down. He's lost a lot of trust. . . .In our family, Niece calls him Grandpa, but my husband's still quite angry with him and Niece is still not allowed to be alone with him. And that's just the rules that we've set. So there's some tension there. I lost a lot of respect for the fact that my little brother wanted to live so bad, and he had the chance and didn't want it. So there's still some – there'll always be that. I'll probably never fully forgive that. I think it would have been easier had Ray not passed away. But in the circumstances that he did, it was pretty tough to swallow. And for me, I'm such a protector of my mom. And my mom's forgiven him and, and everything. But, it's the same with my brother, when he could do things like that, to my mom, with everything that's happened to her, it's pretty hard to forgive."* Although Sister shared her thoughts in the family interview, she added: *"I just try not to rock the boat. So I keep a lot of my feeling to myself. I'm very opinionated. So I try to keep my feelings to myself, just to . . .keep the peace."*

Mother and stepfather are presently living apart but consider themselves very much a couple. *"And Stepfather really struggled with losing Ray and he needed a change. . . . And at first we said no, and then we examined it and decided it would be, financially it made good sense. Career-wise for [him] it made good sense; and emotionally, for us, I think it made good sense because we grieve differently. . . .I need to be around people . . . I energize from my family; and I energize from my good friends. . . .And I need to be with people. I also need some time alone, but I really get energy from being with people I love. . . .And Stepfather is a much more private person. And he likes to spend a lot more time alone and quiet. And we're finding ourselves being at, at odds with that. And he'd get very distressed if I were talking with somebody on the phone, and I'm really crying. But it's - I'd find it therapeutic for me; but it was very distressing for him."* The couple decided in the last couple months that while Mother's home is still very much Stepfather's home-- they view him as being away at 'camp'-- creating of physical distance would allow them both to grieve in their own way, unimpeded by the other. While it has brought some negative changes, most have been positive, Mother says: *"Oh, there's intimacy changes, definitely. And that, I think, just comes with grief . . . .But Stepfather and I, we have such a unique relationship. He and I were best friends before we ever became a couple. . . .So we have this very strong friendship and respect, and professional respect, for one another. We had a very solid foundation . . .but, we had to really; it would have been very easy to lose that. . . .We very nearly did. But, we were able to pull it together. And some of that, I think, is because we had such good communication. . . .So we were able to be very honest with one another."*

Brother, the eldest child of this family, suffers from a mental illness that has over the years created difficulty in the bonds of these family members. Mother says: *"Well Brother struggled. . .with Brother, you have to be sort of careful, because he'll take things too far."* But she adds that he has done his best to be there for the family: *"He was here every day. . . .And it's just, like we'll find, like he'll say to me things like, 'Oh, mom, I saw Benji.' And I said, 'Oh, yes.' And he said, 'And I told him.' And I know exactly what he's saying. And I said, 'What did you tell him, son?' 'Well, you know.' And I'll say, 'No. I don't know, son. What?' 'Well, about Ray.' You know, but he has a hard time."* As Brother struggles to maintain his life and live on his own, he must focus on himself and at times can be demanding of the resources of the family. On his deathbed, Ray made him promise that he would continue to work hard to maintain his life, a constant struggle for Brother who wrestles with suicidal ideation. Mother recalls Ray's words: *"Before Ray passed away, he made him promise that he would be okay. . . .But he said, 'You know Brother, I want to live so badly and I can't. You have to promise me to be okay."* Brother's presence in the household can produce tension due to his demanding behavior, especially for Sister, who has always felt the need to mother him. Sister says: *"And I'm trying to be understanding, but not everybody can react the way I do. Not everybody can react the way Mom does. And Brother has his own reaction to it. It's just Brother and I have a previous history of not always getting along well. And I almost feel like I mother him a lot."* Brother maintains the family routine of Sunday Family Day and is working hard to try not to demand more as he is aware of the sadness and pain all family members feel in Ray's loss. Of these Family Days, Mother says: *"Sundays are our family day. We're always together on Sunday. . .most of the time we're together on Sundays. We have a family meal together and a gathering and that. My whole family."*

Brother's grief is often more silent than other family members. He will sit with the family as they tell 'Ray stories' but he cannot contribute his own thoughts to theirs. He will spend hours in Ray's room, alone and crying, laying on his bed and at times looking at his things. Mother explains it this way: *"He does, it's not that he doesn't, but he just finds it so painful. He'll come over and he'll say sometimes, he says, 'Mom, I just miss him so much that it just, you know that I'm just aching.' Or he'll go and he'll sit in Ray's room and he'll cry."* In spite of the history of difficulties, Mother sees that Ray's death has brought some unexpected changes for her and how she relates to Brother. She says: *"But it also led, the positive thing is. . .I don't have the energy that I had any more, that I used to. . . .I used to, no matter what, I'd smile and take some more. . . .I don't do that any more. And it's not that I'm still not, I consider myself quite a kind, caring, compassionate person. And I still have that. But I also know that I have to take care of myself a little better. I used up everything I had. . . .And, some of Brother's behavior, in particular, he's 21 years old; he needs to start being an adult. I've always sort of protected and done for him . . . .It is, because ultimately, he does need to be a healthy, independent adult. . . .In the long run, it will be better for Brother."* In addition, Sister has also worked to create a different relationship with her surviving brother. She adds: *"I have this idea; I see how hard it is for Mom since Ray passed away, and when he makes it harder, that puts a strain on all of us. . . .Brother is very selfish and self-centered. I try not to talk about him in front of my mother, all that much. But Brother, he's selfish and, where I really struggle is his relationship with Mom. . . .Mom's gone through so much with Ray. She doesn't need any more on her plate. And Brother just can't seem to give her some slack. . . .But when we're all here together, it's good. When he wants to be good, we get along great. . . .So, Sundays are usually pretty nice."*

Grandmother, who lives in an adjacent province, came to assist the family in caring for Ray. Hers was a firm and steady presence to Mother and Sister. She recalls: *"I couldn't do much for Ray, but I could look after his mother and stepfather. . . .And make them eat their vegetables [laughs]. . .sort of thing, and so I did that."* She adds that during Ray's illness: *"We were just together there every day. And I would cook and clean and go buy groceries and monitor the phone calls. . . .And I just, mostly I just sort of sat beside him. . . .And I would just get up in the morning and oh, I'd do laundry, cleaning and buy groceries. . . .And we'd just talk and visit and maybe watch a little T.V. . . .And sometimes Stepfather and Mother would go out for a few minutes. But then I would stay there with him, and he wasn't very conversant. . . .He was quite ill and quite weak."* Her steady presence and many contributions were invaluable to the family, Mother says: *"My mom would come. She'd spend a few days; she'd go home for a little bit. Because she* *felt she wanted to be here to be supportive, but she also felt that we needed time with Ray, too, without her just being here."*

At times, Grandfather would fly in to give her and the family added support. He is a firm, almost rocklike, presence. Mother says: *"My mom has always been very close. And my dad and I are close too, but Dad and I can argue. We always make up, but we can argue. He can drive me crazy just like I can drive him crazy. But he's become a lot mellower. You know, losing Ray has had a profound impact on them. And some of it is losing Ray, and some of it is seeing their daughter grieve. So it's really; it's changed some of the dynamics there, in a better, I think, in a better way."*

The news of their grandson's impending death was devastating. Grandmother recalls: *"We tried to keep a stiff upper lip . . .and encourage Mother and encourage him. But, as time progressed, it became more and more evident that he wasn't winning the battle. . . . And we were so. . .sad. . .And so afraid. . . And it made me so damn mad. . .that somebody like Ray, who was so truly good. . . .Would have this horrible disease descend on him. . . .And then the evaluation day came. . . .And that was the most awful day of my life. . .and I knew what to say to Mother, but I didn't know what to say to Ray. . . .And I didn't, when I came into the room, I didn't have to say anything. He just opened up his arms. . . .And we just hugged each other for a long, long time. . . .And he told me he tried as hard as he could. . . .And he was; the look in his eyes. I will never, ever forget the look in his eyes. He was so desperate for somebody to say, 'It's a mistake.' . . .But he was so good. And we just got through it. . . .And we just. . .that same day Grandfather came."* Mother adds: *"And the day that we got the news that: things hadn't worked. And they came home that night, and Grandmother said Grandfather sat in a chair. And she said, 'I have never seen your dad look so sad.' . . .And it has, it's changed him. It's mellowed him. . . .And he's much softer with me."* During Ray's last weeks at home, Grandmother returned to her home to give this family space to say their goodbyes.

She then returned with Grandfather to assist the family with the 'Celebration of Life' (funeral) and say their goodbyes to their grandson. Grandmother recalls: *"Well, the day before the Celebration and the day of the Celebration, there was a zillion people around. And so we mostly just reminisced. . . .And visited. . . .And then the following day, Uncle and Aunt had to leave because they had other things that they had to go to. . . .And it was a good family time. . . .It was good. It was good to have both my kids there. . . .And we were all just kinda leaning on each other. It was good. . .We talked a lot about* *him. . . . Grandfather gave a talk, at it. . . .And it [the Memorial service] was so beautifully done! . . . It was a beautiful tribute to him."* She provides a grandparent's perspective, understandably different from a mother's, on the importance of Ray's father and his family's presence at his dying and celebration. She views it this way: *"I felt very sorry for Ray's father. . . .He has his problems, but I know that he loved Ray. . .he was very sad . . .he was very quiet. . . .And his parents were there. And I felt sorry for them, too . . . . They loved Ray very much. . . .The time came that it was okay to tell them [Ray was sick]. And they came from [many kilometers away] to see him. . . .Well, I've known them for many years. . . .But we really haven't had that much contact. . . .But they're GOOD people. For sure, friendly, they're good people. They're very caring. . . .They loved Ray, too."* Mother saw it this way as she tells of Father's and his parents' last visit to Ray: *"They were only here for two minutes. And then Ray, because he just looked at his dad. And it was just kind of that look of. . .there was no sort of warmth in Ray's look. It was just he was just looking at him. . . .And his dad came and he said, 'Oh, Ray. I've missed you so much.' And I squeezed Stepfather's hand so tight I'm sure I just about broke it!"* She adds that at the celebration: *"His father came. . .his mom and dad and a couple of aunts and uncles were there. . . .The one thing I wouldn't do, though, was, I would not let his dad's family be involved, because everybody who participated was there from their heart and they loved Ray and they were there for him. And Ray's dad's family weren't. And I could not allow them to get up and say how much they loved Ray because that . . . just wouldn't fit. It wouldn't fit. It was fake . . .I'm not saying they didn't love him; but they weren't there for him."* Further, she is disappointed that Father has not learned much, it seems from Ray's death: *"But he hasn't been able to connect with Brother, either, to say, "How are you doing?"*

Due to geographical distance, Ray had been somewhat unknown to Grandmother but, during Ray's final days, he and Grandmother had formed a loving and close bond. Grandmother says: *"I think that if we would have been fortunate enough to live closer . . . we would have developed a much stronger bond . . .but he was so brave. . . .He was so good."* Grandmother's grief is private; rarely does she share it, even with Grandfather or her friends. She instead spends many hours in her garden thinking of her beloved grandson, remembering his loving nature, and worrying about her daughter, granddaughter, and great-granddaughter. She says: *"I probably wouldn't call anybody. . . . Well, I walk around sniveling. (laughs) Probably, if it's not raining, I would work in my garden. . . .Or I would read."* When Mother phones, needing to talk of grief, she listens for hours and silently weeps with her daughter, whose pain she would like to take away, but cannot. Grandmother adds: *"Well, I think I've helped Mother. . . .Just because we are very close. . . .And, so I think. . .just sharing the grief with her has helped. . .a lot."*

She feels helpless, at this time, in part because of the physical distance between them, but also because she does not understand why one so young and so full of life was taken when she who has lived a long good and fulfilled life remains on this earth. Grandmother thinks that eventually you come to accept it without really understanding. She says: *"Of course you know the old saying, 'They've gone to a better place.' But instead of being comforting, it just kinda makes me mad. . . .Because, he didn't want to go to a better place. . . .He wanted to stay right here. . . .But I'd rather have him right here where we can see him and talk to him and hug him . . .I'm having lighter thoughts. I can think about Ray now without too much grief. . . .I 'm still stuck in his illness. . . .I know when my mom died. . . .I felt very sad. . . .But I could handle it because she was older. . . .She was in her 80's . . . .And she had voiced to me that she was ready to go. . . .So, when she went, it was okay. . . .But, when my dad died, he was just 59. . . .And I had a HARD time getting over that, too. . . .But, eventually, it does happen. . . .And I know that it will happen with Ray, too. . . .But it just takes time; and it's only 7 months."* She adds, *"If you just hang on to the thought that, your loved one (sighs) isn't; his body's gone but his spirit is still there. . . .And just let yourself grieve, but allow yourself to get better. . . .Allow yourself to move on. . .I think it's important. . . .And you have to know that it's okay – to let go of some of the grief. . . .But that doesn't mean to say that you're forgetting him or that you're honoring him any the less. . . .I have to really tell myself that. And then, if you tell yourself that, you do get to really absorb it. You really believe it. . . . And it's powerful. It's very helpful."*

She and Grandfather do not speak often of Ray between themselves. Grandmother recalls: *"So then Grandfather and I came home. . . .It was much quieter. . . .But just between Grandfather and I though, we just look at his pictures. . . .And just talk about him and remember him."* Grandfather comes from the 'old school' where men must be stoic and strong for their family, never letting their emotions get in their way as family leader and protector. Mother says: *"He'll sit while we talk. But he's not a big contributor. . . .I think it's because he doesn't trust himself yet that he [pause] I think he's afraid that he'll either cry, God forbid, it's a big thing."* But he allows glimpses into his sense of loss, as he walks along the beach gathering rocks and bringing them home -- a favorite activity of Ray's. He places his most treasured findings in front of Ray's picture.

Mother remembers: *"We'd pick up a rock, and we'd bring it back. We've got a basket of rocks. . . .And my dad, he picked up a rock and he put it by Ray's picture, which my dad would never have done before. You know, he would never have done that before."* Mother cherishes his words: *"But even right after Ray passed away, we were in the kitchen, and he said to me, he said, 'Just because I'm not crying doesn't mean I'm not grieving."*

His friends grieve his loss through their storytelling with one another and sharing these with the family. They took on a project to fundraise for one of Ray's special classes and with Sister as family spokesperson and leader have been very successful. Mother says: *"Ray's cancer was so rare. And then his school, in Ray's memory, raised $106 000 to donate, because when the kids would come to visit at the [local children's hospital] there was nothing to do for Ray. . . .There was very little that he could do. And he would be bored. And so his friends felt so bad, so while Ray was still alive, they would talk about: they were going to fundraise for a Teen Room."* Sister has been the family spokesperson for the project: *"I kinda got nominated for that, just because I'm the only one who can seem to keep it together the most, apparently, I guess. (laughs) But I enjoy doing it. I enjoy talking about him. . . .And helped out where I could . . . .Organizing and, and that type of thing. So, I very much enjoyed being a part of it. It was good for me."* His close friends, whose parents are also friends of Mother, provided the family with a Christmas gift-- a framed portrait of themselves and Ray in a frame bearing the words: "Forever Friends." Mother gained support knowing that Ray is remembered, and Sister benefits on the distraction and busyness the fund-raising activities bring.

After only seven months, the pain of loss remains strong for these family members. They are actively engaged in their work of creating an ongoing place for Ray in their family. They do so in many ways and through many stories. In the Myhre family, traditions have always been important. In their first Christmas without Ray, they had to work hard to maintain their traditions, but felt it was imperative for their ongoing life as a family. Mother says: *"Christmas has always been sort of an important time and we have our traditional things that we make. And this year, I have to set the norm of what's normal for my family. And it was important to Ray, before, in the hospital he said, 'Mom, where are we putting the tree?' . . .And talked about things about Christmas. And so, I wanted to make sure that we carried on with Christmas like we always did. We have certain things that we bake. Ah, you know, we have ways that we open our gifts before we eat breakfast."* Sister adds: *"And it was important to us as a family that he's gone, but* *we still try and remember that we also have each other. And we try and keep things as normal as possible. It was very quiet. Usually Christmas is quite a hustle and bustle. But I was glad. I had kind of envisioned this Christmas with no tree, Mom in bed. But it wasn't. And that's because we knew that's not what Ray would have wanted. So . . . we tried to stick as close to a normal Christmas as we could, with the turkey and the tree and getting together and the presents."*

Another important time of remembrance has been setting a tradition for Ray's birthday. In this difficult year of firsts, Mother and Sister tell of their plans: Mother: *"Ray's birthday is coming up and that's going to be really, really hard."* Sister: "*Depending on where we are, we all agreed that [day], we'd have Dairy Queen. . . .When Ray was sick, Brother-in-law and I, quite often he couldn't stomach anything, so quite often he would phone before we came to the hospital and say, 'I want Dairy Queen.' And so we would stop at Dairy Queen on the way by, pick him up Dairy Queen."* Mother: *"I've asked everybody if, wherever they're at on that day, if they will have soft ice cream and think of Ray. . . . Because Ray loved Dairy Queen ice cream cakes. . . .That was always what I'd get him for his birthday."* Grandmother and Grandfather also remembered Ray: *"We haven't, well, of course, with his birthday, [laughs] the special thing was the soft ice cream. . . .That's a special memorial."*

Over the months since Ray's death, Mother has had time to reflect on her grief and mourning. She says: *"I go to sleep thinking about him. I wake up thinking about him. He's always, no matter how busy I am at work, he's always right there. . . .Because that sadness always lives with you. . . .Because there's all these things he's never going to get to do. . . .And I'm so sad for HIM that his life was cut so short. . . .And I'm sad for ME, because he's my baby. . . .I really, I MISS him. . . .And then I usually, at least once a day, I still have a very overwhelming grief, where I have a cry. . . .Often there's some sort of, something that's triggered a thought. . . .And, the one thing I've discovered, though, and I always allow myself grief time every day, is to just have a really good cry. And then I feel better. . . .I always know I have time in the evenings. . . .I also think about how I've changed as a person. I really use that time to reflect. . . .I'll look, and I'll look at my pictures and I'll talk to Ray. And I'll, and sometimes just missing him and feel sadness, I'll just have a really good cry. . . .I spoke at Ray's Celebration. And I said, 'It's okay to be sad and it's okay to cry. But it's also okay to remember all those good times.' . . .Because my son was so much more than his death and his illness. You know he was just so much more than that."*

Through these stories and symbols Ray's presence within the family is maintained, as Mother states: *"The center of my life, the core of who I am, is hope. . . .That's always been part: Hope . . . .Hope continues on. . . .And some days are really tough . . . .But to just give up and not get out of bed is not doing anybody any good. . .Ray wouldn't want that. And I don't want that for myself, either. . . .And for my other kids; I have two other great kids. . . .And, I'm more than just Ray's mom. I'm Ray's mom, but I'm also Sister's and Brother's mom."* This family lives on and Ray lives on through them. *"We talk about Ray every time were together. . . .Ray is just such a part of our family."*

"*Like a phoenix rising from the ashes*"
Creating Space for Reformulating Self:
The Story of the Jae Family

The story of the Jae family reveals more individual process than family process but points to the important aspect of the family work of support in bereavement. While Father was willing to take part in the family interview, he was unwilling to do an individual interview stating that to do so would bring up too much pain that at this time he was not willing to confront.

As revealed in Mother's individual interview, it appears Father's role during bereavement, following the death of Sarah, has been one of his own loss in order to maintain family functioning and give support to his wife who has been suffering the pain of Sarah's loss dramatically. When Mother describes the family norms in the early years of their marriage, it appears remarkable that this couple has been able to survive the death of their daughter. She suggests that their communication was poor, with frequent misunderstandings, and the assignment of negative perceptions to the other's behavior. Their definition of family, and understanding of the value of family, was also very different. While Mother worked hard to create a sense of family in their home, Father appeared to have some difficulty relating to his sons, and these young men appeared to hold only a cursory sense of family in their father's home. Sarah's disabilities made it difficult for the family to share activities that were not related to her care.

The family interview primarily reveals the care that was needed to sustain Sarah's life, and offers a glimpse of the reality of family life when a child has such time-consuming needs. In this interview, I was able to get very little understanding as to how they constructed family as anything more than a group of people who provided physical care to Sarah. At times, it appeared that “inside jokes” were occurring between Father and his sons-- jokes that even Mother did not seem to be part of. Even though Brother 2 was a late adolescence and Brother 1 and adult, it appeared at times in the family interview that Father was protecting his sons, (doing so in a joking way) raising the issue of possible coercion of these young men into the study interviews. This issue raises the important question in family research about the subtle pressure put on family members to conform to the needs of the family. Perhaps one that in this family was also true of their participation not only answer is care but in the family work of bereavement.

In the individual interviews, Brothers 1 and 2 could offer little about their sense of connection to Sarah and hence these interviews relate stories of little grief and mourning. However, it is important to acknowledge that their primary home is with their mother, and not Father, hence their sense of family within this home may indeed be minimal. Further, their sense of family is complicated by their age and adolescent need for separation. Furthermore, Sarah's disabilities left her with very little ability to connect with others complicating the relationship between her and her brothers. In spite of all these difficulties, Brothers 1 and 2 are not only willing to take part in these interviews (I informed them numerous times of their right to withdraw participation) in order to support Mother. They have also been willing to take part in family rituals in order to support Mother and Father.

Mother's interview reveals Father's willingness to perform many loving acts of support, which seems has allowed their marriage to survive and to even grow stronger. He has been willing to create space for Mother's individual bereavement needs and she has worked hard to make sense of Sarah's life and death and to reformulate herself as a stronger person recognizing her capabilities to sustain her marriage and work toward creating a new family through the hope of other children.

Telling the Story: The Spirit of Sarah

Mother wrote this story of Sarah's short life. “*Ten years ago, I gave birth to a beautiful red headed angel with green eyes and curly ringlets of hair. She was my absolute pride and joy and with my husband's two other boys it made our family complete. Sarah was our unexpected bundle of joy. . . .As my daughter was nearing a year old, she was not making her baby milestones. . . .(We discovered) that our daughter was born with severe brain damage and her development was delayed permanently. . . .I was quite busy with his two boys and being a full-time caregiver to my* *daughter who required 24-hour care. I became skilled at maintaining my daughter's health, despite the fact that she lived with an intractable seizure disorder. Unfortunately, not all the love and care in the world could keep her alive and March 23, 2005 she succumbed to a bladder infection along with strep throat and died."*

Father tells of the work to keep his daughter alive, "*(We) got very little chance of ever controlling the seizures. . . . So we then started trying to treat the seizures which seemed to accelerate the seizures. You know, she seemed to start having lots and lots and lots and lots and then they would start to affect her . . . her abilities. She started being unable to swallow and unable to crawl and very soon, she started deteriorating and we tried different medications which caused worse problems for the most part. And initially she lost the ability to eat and we had to have a G tube put into her tummy so we could feed her, that way and then that initially showed . . . some progress because she stopped having seizures for quite a while. Then I think after a few months they came back and knocked her development back and it took her a long, long time to learn anything. And she would sort of learn and start to make a bit of progress and a bunch of seizure would come and strip that all away and then some. And she would struggle and learn some more. And eventually we had a routine . . .that was pretty straight forward, for food and medication and everything else and. . .we monitored everything. We had an aide come in three times a week."*

Sarah's step-brothers, too, were involved in the work of Sarah's care. Unfortunately, the work could get in the way of connecting with her as a child. But a strong spirit of Sarah remains in the house, from her "princess" room to the many pictures and items throughout the house. Most importantly Sarah brought unconditional love to the Jae family. Father brought his love of music to his daughter. Mother reports that, *"Sarah was his unconditional fan. . . .It didn't matter what the heck he played, she loved it. If he just even touched the guitar. . . .He never had that in his whole life and when she died, that went."* Sarah brought motherhood to Mother. "I *was her mom! . . . I learned so much [from her]."*

The Family

The story of the Jae family begins when Mother and Father came together when they heard the news that Mother was pregnant with Sarah. Mother says, "*We were kind of dating, and it was within the first month that I kind of decided that he wasn't really the guy for me and I discovered I was pregnant. Then he convinced me to continue with the* *pregnancy. It was a very rocky nine months because we were just getting to know each other. . . .And we, I just wish that I had more time to sort things out before I gotten [sic] so seriously involved. And then all of a sudden, there's the responsibility of parenting and we're on very different ends of the scales how we parent. It was very trying. And then to be faced with the fact that the child we had together had major disabilities and we didn't understand what that meant for the future. And then was very stressful because she cried so much, and now I know, not like any normal baby would have cried. She just cried so much. It's amazing we are still together. It was very, very stressful."* Before Mother and Father had time to forge as a couple, they were thrown into full-time caregiving of Sarah; days that had Mother going for 18 hours with little time to consider her own or Father's needs, much less those of her two stepsons who lived outside the house.

Mother had come to this family ill-prepared with skills to seek her own identity or create a structure for her family. Her family of origin was a hostile environment where she often suffered neglect and abuse, resulting in her entering her relationship with Father without a solid self. Mother reports that Father had been brought up in a family who were supportive, but somewhat distant. Communication in both homes was limited and superficial, leaving Mother and Father without the skills to enter into a relationship where they could understand one another. The couple separated twice during Sarah's life, each unable to cope with the relationship in the face of Sarah's increasing disabilities. Mother explains, *"The first time we separated, it was three months. And the reason why was that Father was having a hard time paying the rent. And I needed more stability in my life. The second time we separated was that. . . .She went through like non stop, she screamed for 9 hours. And she would cry and scream and I would phone Father, because I had nobody. And so I would call Father at work, which made him not very happy and me kind of grumpy. And so it caused a lot of stress between the two of us. . . .And I think that he was at the probably, the pivotal point where, that he was absolutely hating his job and very resentful with the fact he felt trapped. That and, I was seemingly having a very, most excellent life staying at home with Sarah. And I had my own things going on. But we just got into a really big, bad fight and just had to separate again. And it was very much longer than and it seemed more permanent this time, but once again he surprised me. And we went for couple's counseling and worked out a lot of feelings of anger I had towards his family in the sessions. And he seemed really willing and wanting to come back and we kind of starting putting the things that caused* *so much trouble behind us. And I think his lack of commitment felt like-- towards Sarah— was huge to me. And once I said that if you loved Sarah just a little bit more, that's the key to being with me. And all of a sudden it was like, "I'm there!" And he was, much more you know."*

Mother also describes a separateness between Father and his sons. The teenage boys live with their mother and visit the household on weekends. But there had been little time for family activity both before and after Sarah's death. Mother states, "*And yes, and we had to plan everything around HER. And we did try and make, like do things with them as well, go to the movies and soccer. But he [Father] was very tired often on the weekend and he didn't want to go and do anything. But sometimes we went and did stuff."*

In the family interview, much of the story the family tells is of the work it took to maintain Sarah's life. The young men's relationship with their sister was limited, in large part due to their primary home being elsewhere. But adding to it was their sister's disabilities and the limitations this imposed on her ability to form relationships. As time moved forward for Sarah, from birth to her death, she was able to relate to her world less and less. Although the brothers spent time assisting with her care when they visited the home, there was little chance for them to truly connect with her. Brother 2, perhaps, as a factor of age or personality, made more attempts to interact with Sarah oftentimes 'playing' with her and her toys. For both young men, visits to Father's house became ones that caught them up in the frenzy of taking care of this severely disabled child and gave them little time with Father or their stepmother. When Sarah died, as a result of a seizure disorder from a "massive brain anomaly," everything this family knew about functioning as a family fell by the wayside. Brother 2 reports, "*We were just sitting around not really knowing what to do with all our time."* Mother thinks, "*So about the boys . . .well I don't know. I think they honestly do miss her because she was such a big part of our lives."*

But there are few stories of Sarah, perhaps because of her severe disabilities, that allow family members to reminisce and for them to use as a group to incorporate her spirit into their family restructuring. Family celebrations of birthdays and Christmas were really about Sarah, so now these family times often go unmarked. Father states, "We don't do Christmas anymore." As organizer of the family and family activities, it is no wonder that when Mother was not able to function, the family had little interaction and the brothers were seldom present in the home. Father realizes, "We're still dealing with using [our] time." Their story is one of four individuals seeking to make sense of the world they now occupy.

For Brother 1 and Brother 2, grief holds little place in their world. Brother 1 reports that, *"It was sad. I missed her." But he adds that he could feel her loss more intensely when at Father's house because," Well, here everyone was kind of sad, a lot more sad [sic] than at my mom's house and it was kind of like normal. There it was normal. [But] I don't think it really affected me much. . . . I kept to myself. Like for my friends, for instance, [what they noticed was] not much different."* He noticed his grief subside, "*maybe about a year after. . . . Well it gradually decreased in that time . . . a slow change."*

Brother 2 faced a similar experience. He reports that at the news of Sarah's death, "*I was really sad, ah when I found out and then . . . .I was pretty sad for the next couple of weeks but then ah it got better after."* On the day of the funeral he remembers that, "*Everyone was pretty sad . . .it was kind of hard to see her lifeless. . . .I think I was shocked and surprised that (pause) it was, just kind of surprising to me."* He sat with family, "*my aunts and uncles and cousins"* during the service and then had *"a meal at the hall first, and then we came back and some close relatives and friends of my parents came [back to the house]."* He expressed his grief by crying. Unlike Brother 1 who had not told his friends he had a sister, Brother 2 had shared with his friends that he had a sister who was ill. But neither brother directly told their friends their sister had died. Brother 2 however tells that his best friend, *"Well he knew about it, but I didn't tell him."* Nor had he told anyone at his school of his loss.

Both brothers noticed their grief more at Father's house than at their mother's. Brother 1 says, "*Well at my mom's house there's things distracting, like T.V. and games. A lot of the time the T.V is not on here."* Brother 2 adds, when he returned to Father's house, he noticed that, "*Sometimes Mother would be really sad and ah other times she wouldn't. . . .He [Father] was pretty sad too, most of the time."* Brother 1 sensed that Father and Mother needed more help with household chores and provided that help, "*I mean, I did help out around here a lot more than I did before."* But now, after 2 years, he finds, "*Well, I don't really help out as much any more."* In large part, he does not sense the same level of sadness that existed in the first year. He rates the sadness now as a 2 on a scale of 1 to 10. But "*Mother's a bit more sad [sic] than Dad.*"

In large part, Sarah's death did not change their routines. Mother comments that she thinks they distanced themselves even more from the household, stating, *"We did* *more, sort of activities before she died, then afterwards, because the boys really didn't come around. . . .I think they were uncomfortable. . .because they have to come, time and time again, and she's not there. . . . I did think that was for six months."* But, she understands, as does Father, that they are just busy young men with busy lives. She further states, *"And no, it's just because they are boys and they have their friends and stuff you know. Brother 2 now has a full time job and Brother 1 is really tight with his friends over there. So to come, it would interrupt that. . . .But the thing is like Father got sick. And then they came around lots for him."*

To date, Mother and Father have been occupied with their own grief and unable to address the restructuring of family. However, it is interesting to consider if it is ever possible for families at this stage of life, the time of adolescent separation, to restructure themselves and incorporate a member who has died, at the same time as working to restructure family with other members whose work it is to separate. While Brother 1 and Brother 2 are not often present in the home, both will visit when invited and in particular, they are always present when Mother and Father celebrate Sarah. Brother 1 feels that he does not need visits to the cemetery, or family time, to reminisce in order to deal with his grief. He states, "*I don't like talking about my feelings.*" But both young men are always in attendance at these family remembrances-- loving acts performed willingly as they recognize Father's and Mother's pain. Brother 1 takes part in family remembrance ceremonies because he feels the need to support Mother and Father during these difficult moments. *"Not like but that I need to do it. . . . I think Dad and Mother would be pretty disappointed if I said that [I did not want to attend]."* However, Brother 2 states he likes to remember Sarah by "*just sharing memories*" and reports that, "*It felt, it felt kind of good [going to the cemetery on the anniversary of [her death]. It helped."*

While Father chose not to take part in an individual interview, we gain glimpses into his reformulation through his words in the family interview and through Mother's comments. Father reported when he chose not to be interviewed that he just wants to "*forget all that pain and get on with life; I don't want to dredge it up again."* It would appear from this statement that Father is still suffering. His words at the end of the family interview indicate some movement, but only glimpses. He says, *"[I] don't have to feel guilty about not feeling so sad any more . . . .as time passes you find there are moments where you really are not totally sad and in fact, in some points in time you find yourself starting to feel happy. . . .When you're in a bad mood or having a bad grief. . .*

you can just let it, let your emotions be, because they'll, fade a bit." He also learned that grieving *"helped me open up a little bit."*

Mother tells a poignant story of Father as a musician. Father had been performing for many years when he met Mother-- in fact it is at a folk festival where they first met. She reports, *"Father's a musician and he needs to play music you know. And I wouldn't love him as much if he would have said, "Okay, I'll put my guitar away" and say he'll, doesn't ever play again. Like that's not who I like. The essence of Father is a musician, very much so. I want to encourage him and I have always encouraged him to join bands and be part of it because he needs that."* But when Sarah died, Father stopped playing his guitar. Even though Mother encouraged him to perform on stage, he was unable to do so. It took some time for Mother to realize that music was just too powerful a reminder to Father of his loss and that it triggered his pain. She says, *"When Sarah died, he played guitar for her, and I never realized it--that this had a tremendous impact. As I didn't realize it until the fall of the year after. We had to buy him a new instrument because he could not play the guitar any more. . . So it was pretty devastating."* Mother's support extended to buying him a new instrument-- a mandola-- which he was able to take up. This led to his ability to once again perform in public. One can only speculate that perhaps his return to music has allowed him to begin emerging from his suffering.

In this family, Mother leads the way in remembering Sarah and restructuring the family, but in order to begin that family work, she first had to do so by reformulating herself. She recognizes that while this work of examining her identity was primarily hers, it could not have been done without the support and loving acts of Father. She says, *"But all in all through the whole thing, Father always showed me that that he cared about me. And if I cried or something, he would give me a hug, or and maybe he wasn't crying, and maybe he was seemingly thinking that he had to be strong for me. I don't know, we didn't talk about this. But the thing is I know he did show me a tremendous amount of compassion."*

She recalls that she was only 16 the first time she and Father met while he was performing in a music festival. They joked around, and he told her that one day he would marry her and give her a baby. This prophecy had long before been forgotten by the couple. But remembering the story was crucial in allowing Mother to see the important role that Father played in her life for a long time. At 16, she had been forced out of her home and was struggling to survive. The sense of security that Father held out was unfathomable to her at the time, but later she again experienced this glimmer of stability when they began dating and soon after learned of the pregnancy. While the couple struggled severely in their early days together, Mother now realizes that the seeds of a stronger relationship were present all the time. While she often blamed Father for what seemed to be his resentment of Sarah, she has come to realize that it was his own identity struggle which brought forward this resentment and anger towards her. In observing his grief, she has witnessed the strength of his bond with and love for their daughter, and this has allowed her to view him, and their relationship, in a very different way. She has been able to forgive him and let go of the impression that she carried for a long time that he did not love Sarah. *"I spent a lot of time resenting Father because I didn't think that he loved Sarah as much as I thought he should. . . .But I didn't give him credit for the fact that he just is so introverted, into himself and it took him a long time to be able to grieve and to admit some of the depth of his feelings. Because they are there. And I just resented him for such a long time, and then I just started to realize that was really dumb."*

As she emerges from her own suffering, she is able to recognize her strengths and the silent strengths of her relationship with Father, adding, *"The last two years has given me a chance to really look at him in a different way . . . and then, letting go of that resentment, but just realizing that he can only take so much in his personal life. And yes, he's let us in but . . . he has walls and it's got nothing to do with me. . . .Once I came to accept that, I realized that he did love Sarah. . .[before] he rejected her because he was terrified of what was involved. . . .But, you know, he stepped up to the plate and he worked really hard for all of us. . . . and he hated his job . . . [but he didn't leave it] so we could provide Sarah with excellent health benefits."*

Throughout their two years of grief, Father has continued to perform loving acts towards Mother. He remained with her despite her demanding behaviors during her grieving, *"I wasn't grieving beautifully. . . . I was just grieving the way that I felt worked for me."* Many times she would phone him at work demanding that he leave and come home so that she would have the opportunity to talk. It was difficult for Father to be present at times of such sorrow, but he remained in a job that would allow flexibility. This flexibility allowed him to take phone calls and extra vacation time to support Mother's needs. It appears that in supporting Mother, he may have put his own grief on hold, enduring in order to preserve his family. In doing so, and perhaps without realizing it, he has created the space for Mother to reformulate and perhaps her reformulization now allows her to lead the way in restructuring their family.

Mother's work has been to create a new and strong identity. During Sarah's life, Mother identified herself as only a parent, "I was her mom!" and "Sarah was the focal point." So much focus was given to Sarah's care, and maintaining her life, that there was little time for other family activities. Of this time, Mother reports, *"We sat down and talked about how time-consuming that she was. And of course, it is difficult to say these things because you want to say in the same breath how much you loved her. And that we would do it again; it would be nice if she could come back. But the thing is like when Father said, 16 hours a day I was occupied. Hello, yeah! I was quite occupied because that thought was in the back of my mind had to be seven steps ahead, always making plans and I was. You know and that, in itself, took me away from Father. And I wasn't available as much, because with a baby, you are quite busy for the first year. And then the baby starts to break away and starts to grow up, and doesn't need you as much, then can play outside in the backyard and sort of things like that. But with Sarah, everything had to be arranged. And it's like it got really exhausting. . . .There is no part way. . . .And even when she's sleeping, you had to go check on her you know. And I don't know . . .I would wake up at night and I would know that something was wrong with Sarah. So I would go downstairs and sure enough something was wrong with her, so sure, it was constant. You know somebody called me being over- vigilant. I wasn't. It is just the way it is."*

Shortly before Sarah's death, Mother obtained an art studio and created a bit of space for herself. In her grief, her art has taken on a greater importance, and it has allowed her to explore her motherhood and the importance of her relationship with her daughter. She states, *"When she first died, like I said, it was just unbelievable. But I had the studio and the thing is, even though I could only come here four hours a day because she was in school and I had to be at home when she got there, I was very productive. And then when she died, I had all of the time in the world, so that I could come here as much as I wanted and I did. I started coming to my studio, and I also invested, and also decided that maybe I should go back go school, cause I wasn't able to attend any university courses while Sarah was alive. I tried it once and it just didn't work out. So, that was possible, so I did that. And I started drawing Sarah. And before she died, I tried drawing her and it just wasn't going so well, and then all of a sudden I began to, really draw. So. . .when she died, the talents that I had inside me became* *alive. And I was able to, all of a sudden, draw like amazing! And so I spent a lot of time drawing her. And I drew her for a long time. And I had an art show which was successful, and sold some work and then. After a while, I just stopped drawing her, which is fine too. And I started, you know, making a routine, trying to come to my studio, to have all this time. And I discovered things about myself that I needed to find out."*

It is Sarah's presence on earth and her continuing presence for Mother that has allowed Mother to recognize her strengths and to find herself. *"Sarah gave me a lot of confidence I never had. And then when she died, people came up to me and said how well I was managing everything. And I realized, that even though I had a breakdown, and who wouldn't? Like I had a breakdown in the spring. I have had a lot of, tremendous amount of things that have happened to me. And the more I thought about it, so it's okay. I'm still standing."*

Mother tells the poignant story that, while she was recovering from major surgery, she spent time in Sarah's room—forced there because she could not climb the stairs to her own room. But what had been a place of pain, previously she had entered Sarah's room only when she was in the deep suffering of grief, became a place of healing. The family would gather in the room to watch TV, and even though Brother 2 stated that at first it "was uncomfortable (for him) to be in Sarah's room", it became a place for all of them to connect with one another and perhaps even with Sarah. Brother 2 would often crawl under the covers of Sarah's bed, seemingly finding comfort there. It is in the room, as Mother was recovering, that her cat was dying. And as she stroked her dying cat, she felt that she was stroking Sarah and that once again her daughter was close, *"And our cat was very sick and I didn't know it at the time. But she was on my bed all the time and I just sort of imagined when I was petting my cat I was actually touching Sarah, because it actually felt like the same thing. And I imagined her being there with me. And it was very peaceful because I was sleeping in her bed. . . .And I started to really let go of a lot of things. And as I told yesterday, I had this dream. . . .And I really felt like Sarah had been in our house. I don't know why. And that her spirit was in our house. And after I had the dream you know, it just felt like better. [But]I can't tell you that every day is perfect."*

During this time, Father once again showed, through his loving acts of caregiving for Mother, his love for her. These expressions allowed her to understand that she was worthy of love and deserving of a happy life—a feeling she had never experienced before. She recalls, *"I was thinking about that how I grew up and how I am living my* *marriage now, very different. Very, very different. You know I am able to ask for what I want, and be happy and my life is very stable. . . .My parents' life was definitely very different. And I'm very proud of myself and I watched my mom being miserable. And I learned very early in the marriage just to say okay. You know he's not a mind reader, he's not going to guess; you have to say what you want, be specific. And you know what? Father, he has really tried—all along."*And she has new hope for herself and her marriage, "*Because the marriage can stay together.*"

These acts and the connection with Sarah's spirit, were able to allow Mother to truly feel the depth of her pain in the many losses she had experienced in her life-- her abandonment by her parents, her mother's death, her lost relationship with her brother and his family, her failed former relationships-- but as well, she experienced a freeing from this pain. As she experienced her own joy in being a mother, she was able to confront her pain in the death of her mother and their lack of relationship. She connected with a strength that had always been there, but that in her grief she had forgotten. She says, *"When we had the funeral I was a much stronger person in the sense that I was able to get up and talk clearly without breaking down, and stay on track. Like we had a program we were trying to present. . . .And I think that coping mechanism comes from dealing with all the things I have had to deal with all my life. I just learned how to just, to at the time be able to cope in a crisis, sort of, situation and be able to function normally."*

For her, being Sarah's mother, in spite of the overwhelming burden she sometimes felt, allowed her to understand her strengths. In her grief, she realized that the life and death of her daughter reformulated her into a person she had never understood that she could be. *"It just, it changes your life forever. . . . Having a child die is just so different. . . It's an end to your hopes and dreams that everyone, every parent experiences for their children. Their future is just gone . . . .Even though your path takes time you will feel better and then there will be days where something happens and you are just . . . it seems like you go through this, to me what it feels like a very dark period and then you sort of, I don't know, start to come through the light and come to an understanding of what it is, what it means to you that you know that your child has passed away. . . . It doesn't have to be totally devastating. I mean it is, but it doesn't have to be. There can be, there can be positives from it. Like a phoenix rising from the ashes basically."*

"I'm still more or less the same person I was, but better because I had him."

Reformulating Self while Creating the Spirit of the Child:

The Story of the Jones Family

The story of the Jones family reveals the conjoint processes of individual and family bereavement. This story is told only by Mother and Father who clearly defined themselves as "the bereaved family" excluding others, such as extended family of grandparents and aunts, or family of choice. Their network of support--both family and community-- is minimal and they have had to learn to reach out in order to receive the support they need in bereavement.

The Jones family interview demonstrates the side-by-side story telling of loss in the death of Patrick. Mother and Father had very different roles to play in caring for Patrick, a little boy with many disabilities but a spirit that could light up any room. While Mother took the primary responsibility for Patrick's day-to-day care, including the coordination of his many caregivers, Father was often gone from home for long periods as the family's primary breadwinner. But Father maintained a close and loving relationship with his son when he was able to be at home. The death of Patrick has been devastating for both parents but their individual response to this loss looks very different. In the family interview they relate the events of Patrick's life and death taking turns telling the story. Further, they speak of the effects his death has had on them as individuals. They continued the stories in their individual interviews. Mother and Father reported that they are neither a couple who communicate on a feeling level, nor do they find it easy to know how to bring comfort to each other. This has created a struggle during their bereavement.

Mother is a doer; she copes by keeping busy. But she has had to learn that grief and mourning require moments of quiet solitude. Father seems to cope in just the opposite way. They have been able to find common ground doing numerous fundraisers and starting a web site in Patrick's memory. These activities have allowed them to find meaning in Patrick's short and difficult life. In doing so, they have been able to confront their loss, value the suffering that is part of it, and give back to others who helped them care for their son. The website and fundraisers also serve as a means for them to create Patrick's spirit as an ongoing presence for them and for others in the community. They delight when the school children come to tell them stories of Patrick as Mother and Father water his tree in the schoolyard. In this way, the spirit of Patrick becomes fuller with the memories of many and is not limited to just those private memories that live in the hearts of these two bereaved parents.

Telling the Story: The Spirit of Patrick

Three years after forming as a family of two, the Jones couple became pregnant. During the pregnancy the couple was informed that Patrick had a mitochondrial disorder that would cause many disabilities and shorten his life. On hearing this news Father was devastated, *"I grieved for the son that I wasn't going to have. And after he was born, I accepted what he could do."* The family's life became very busy, as they cared for a son with many disabilities. Mother says, *"Patrick was my only child. He was a child with disabilities. Who I was for 7 years; I was Patrick's mom, Patrick's physiotherapist, Patrick's you know. . . .is everything. . .Patrick's everything. EVERYTHING."*

The couple was able to adjust to Patrick's needs, and, after the initial suffering involved in grieving for the lost hopes and dreams of their disabled child, they were able to learn that there is value in suffering. Mother says, *"You almost have the sense of sacred. . . .[although] part of you dies as well." But father's deep love of his son helped him to realize, "That's when I sort of started to change. . . . I'm not the person I was before that . . . and I'm not the person I would have been if he [was] an average little boy."*

Patrick's care involved a daily routine that was maintained with the help of caregivers and other social supports. Since Father was often out of town for work, Mother managed most of Patrick's care, including attending many medical appointments and numerous visits to the hospital. Patrick became well-known to the hospital staff on his many visits. But his spirit shone through his many difficulties and he was a favourite of teachers and nurses. Father reports, "*his workers, which were really his friends, because you didn't work with him without becoming his friend."*

During bereavement, Mother struggles with her identity as she works to understand what Patrick's beautiful spirit has brought to her life. *"There's still parts of me that are the same, but there's parts of me that are very different. I've had to learn a lot of things being Patrick's mom. . . .Some of those things are still with me. Some of them are adapted a little bit. I'm still more or less the same person I was, but better because I had him."*

Father remembers Patrick as a beautiful boy who, at age 7, was still loved by all who came in contact with him. While Patrick was alive, Father found it difficult to picture him as an adult, *"For a while I couldn't see Patrick as a teenager, as an adult. And I really began to realize, after I sort of examined why, the reason that I couldn't imagine him as a teenager or as an adult is because he didn't meet my expectations of what a teenager and an adult should be. . . .He should be able to go to High School, get his own car . . . get a job, move out of the house, get married, [and] move along all those things. And he was never going to do that. . . .And he was never even going to use the bathroom by himself. . . .So. It finally came to me that I couldn't see him as that, not because it wouldn't have been okay for him. . . . ecause if he was an adult, and he was severely disabled, and even if his mentality never changed from that of a 6 year old, where he'd like to be tickled, when he was 40 years old. . . . It just finally dawned on me, I guess, that that was his life. . . . nd that was what he got; and that that was the way it was going to be. . . . nd after I accepted that, then I could start to see him as an adult. . . .He was a beautiful boy."*

The Family

The Jones family have had to endure and suffer through Patrick's illness and again when he died. Mother had been brought up in a family that prized independence, *"I've always been the kind of person that . . . just do what I had to do to make the situation work and be independent, and all of that."* She developed distant relationships with her parents. She noticed the distance, particularly following the birth of Patrick when she needed their support and they could not be counted on to give it. While they would at times, take care of Patrick, this was done only when it was convenient for them and when the couple would pay them to do so. Her sister was more emotionally available for her, but due to health problems she could not be counted on to help physically. As a result, this family relied on professional caregivers for support and these caregivers became 'like family".

While distance was created in the couple's relationship by mother's up-bringing and personality, it was also created by Father's job which often took him away for long periods of time. Before Patrick was born, the couple enjoyed activities together, but their communication was somewhat superficial. Mother says, "*I mean we can talk about things, but I mean we've never had the relationship where we're, "Let's sit down for two hours and talk about this and this and this". . . .I mean, you talk about it as it comes . . . .When Patrick was alive and even after he was. . .not with us. Then you just. . .you're having your conversation when you need to. You hear about some people, how they* *communicate about this and that and everything else. . . .And you we'd talk about stuff as you need to talk about it."*

When Patrick became ill and was hospitalized for the last time, Mother could feel the impending change. "*It was my body telling me*"-- the deep bond that she had forged with her son was coming to an end. With Patrick's death, grief in the Jones family not only involved the shock, numbness, and pain they had experienced in the grief related to the news of his impeding disability; but this time there was also a sense of initial relief because caring for Patrick was hard work. Mother recalls, "*But I felt bad, too, because you think your life's easier now. . . .But, it's not, it's harder . . . .Certain parts of it are easier but most of it's harder.* While their life quieted and became "*a lot less paced than it used to be,*" Father found that, "*The silence is just asunderous* [sic]." Creating space for individual grief has been almost a given. Mother has felt strongly that this space is necessary since,"*Father and I grieve very differently; and we'd both be in the same place, but we would both be in totally different places."* But she has also come to recognize that perhaps there has been a little bit too much space, since she has felt isolated and without a support network. But leaning on Father has not always helped her mourn. *"Well, a lot of the times I'd start crying, and then he'd feel upset because he made me cry. . . . And then he would be upset because I would be upset, you know. . . . So, I just, I don't know. I think maybe I needed to separate myself, a little bit. . . . I try to give him the space that he needs."*

Although Father recognizes that he and Mother grieve in very different ways, he feels the space that she often creates between them is too large of a gap, one that he at times wonders how they will close. *"She knows that I prefer that she comes over and gets me. . .some Kleenex. I don't know. . . .She just seems very, very cold when I'm going through a bout of grief. But I do it quite often. I don't know. . . .I'm sure I'd feel closer to her if she came over and just sat down beside me. . . .I've . . .told her that when I'm really hurting, it feels good to have somebody there. . . .But, I don't know, maybe it just hurts her too much to come over and sit down. . . .I guess I've never really come out and asked her, 'Do you want to be left alone or do you want somebody there?' But, I get the impression that she doesn't mind me being there."* Mother adds, *"Father and I grieve very differently. . . .When he's crying I have a hard time comforting him . . . .It's not because I don't want to, and it's not because I'm a cold person. It's because . . .I have learned that each person needs to grieve on their own and you shouldn't necessarily interfere with that. And maybe I've taken that too literally. . . .But I went through the time* *where: I'm not okay for myself, so how can I be there for somebody else?"* Despite this gap, Father recognizes that together they have a membership in "*an exclusive club*" that unites them in their love and memory of Patrick.

In order to create support, Mother has reached out to support groups where she has found an understanding, particularly with those who have lost children. She now understands what it is like to be a member of that exclusive club and how society finds it difficult to talk about the death of a child. *"We don't talk about death very much, we certainly don't talk about death of children very much, and then dealing with a child with special needs on top of all of that . . . .Everybody just goes about their routine and their life. And sometimes you kinda get lost in the shuffle, I guess."*

In an effort to confront his grief Father too has attended bereavement groups and counselling. He realizes, however, that his attendance at groups does not assist him with his pain but simply intensifies it, especially when Mother speaks. *"The bereavement group that we've been going to, I don't find it's doing me an awful lot of good. I don't think I'm in a place to be going to a bereavement group right now. . . . I think I'm still in a place where I just. . .I can't intellectually address his death, yet. . . .And I think you really have to in order to participate in groups like that. . . .Mother triggers me more than anything else. If I'm by myself talking, then I'm not so bad, but if I'm listening to her talk, or if I'm writing and I can read back over what I've written. . . . It just, I've said it before, it just kills me."* He attends the groups as a loving act of support for Mother. *"Over the past year, Mother has done a great deal of work to reformulate herself. She went back to work, right after Patrick's death, and her work environment was very supportive, as long as she was enduring her pain and could focus on her job. But when, after about four months, she could not tolerate being around people and she started to be short tempered, the workplace became unsupportive. I think they always expected me to go there and do my job and do it well. And when I started to struggle, people noticed it. I noticed it. Some people thought, well, it's better for me to keep working instead of being at home, because that may make me feel worse. And so they did things; they wanted me to be there out of my own best interest, even though they could, some people saw that I was struggling. . . .And, you know, maybe I should have taken a little more time, but then if I had, maybe I wouldn't have been able to function as well as I did. I don't, you know, I don't know."*

Mother held on and endured for as long a she could, but it was her body that gave her signs that what she was trying to do was unhealthy. She developed a rash and her doctor told her that this was in response to stress and likely a sign that she was not coping with her grief. She lapsed into a depression and sought counselling to address her grief. *"So once I started getting those reactions, physically, and mentally, [and] emotionally, then that's when I knew, "Okay. Something's gotta give here, because I'm going to wind up in the hospital if I don't make a change in my life."* Mother realized that she needed to give herself permission to care for herself and that she needed to make a choice. *"And I was so worried about failing and not being able to do my job, and letting people down and just a hundred different things. Once I stopped and took time, I've been doing better. I mean your pain's never gonna go away. It's always gonna be there."*

Her own work of reformulating self has been extensive. She has allowed herself to suffer and really feel the depth of her pain. *"Everyone else goes on with their life and you're just stuck at this place you don't want to be in."* Mother has learned to value the suffering. *"There's things I wish didn't happen, but it all needed to happen because they needed to realize I have to put myself first . . .because if you are putting yourself first, you are taking care of yourself. If you're not taking care of yourself, you can't properly take care of other people. . . .Those are the things that I wish, maybe, hadn't of happened, but if they hadn't of happened, then [I] wouldn't be at the same place that I am now."* During that time, she has involved herself with projects not only as a way to endure but also as a way to 'give back', an important component of reformulating self. "I'd like to do the little things that we do in memory of Patrick because sometimes I'm scared. . .and then think, "Okay, well, if I focus too much on the living, am I going to forget things? . . .And that's there, I mean I don't think that will ever happen, but you have the fear. . . .Keeping the things he brought to life [allows me] to carry on."

When others comment on her courage to share her experience of loss and engage herself in projects to remember Patrick, she experiences a growing sense of self-confidence and self-esteem that encourages her to do even more. *"It made me feel . . . confident in myself, because [for] a long time I didn't feel confident. I didn't have any self-esteem, any self-confidence. I just did what you had to do. And I feel those things are better and continue to work on them."* She still considers herself to be a mother. She says, *"I am still a mother, but I don't have a child to show for it."* For seven years she defined herself as Patrick's mother and she now asks herself the question, "*Well, who the heck am I? I still don't know 100% who I am or what my purpose is in life anymore."*

To give her life meaning and purpose, Mother reaches out to others experiencing the loss of a child by sending notes and cards, hoping in some small way to relieve the sense of isolation she has experienced in grief. At some point in the future, she would like to work with grieving families, but realizes that, for now, she must attend to their own grief. "*And I'm still learning to deal with things . . . . Eventually I want to help other families that have lost their children."* As Mother continues on in her work of reformulating the self she feels that, *"I'm learning something new every day. . . .You gotta continue to do that and go [where] things lead you*."

While Mother has been working intently on reformulating herself, it appears that as a family they are only beginning to address their relationship as a couple and to redefine themselves as family. They have learned that, with time, the suffering lessens. While Patrick is always present to Mother, she finds that not every thought is of him. *"Like I know people, they say every minute of every day that they're there. . . .And I think that's true, but I think that if you're spending every minute of every day thinking about that person. . .what kind of state are you in? Like, you can't."*

While Mother cycles back between suffering and reforming the self, particularly in examining her new priorities and in her efforts through her various projects to 'give back', Father cycles between suffering and enduring. *"A year later, I'm still devastated . . . just overwhelmed . . . [and feel so much] physical pain."* Father uses his sense of connection with Patrick to assist him to make meaning in Patrick's life and in his death. In his grief, Father has been able to, *"see the connection between myself and him as being, because of his disabilities, as being so much stronger."* This connection has helped him to realize, "*If you look at it: when would be a good time for Patrick to die? It was probably right around when he did . . . because he was still small. He was still really cute looking; he was still a beautiful little boy."* But even in trying to make sense of the timing of Patrick's death, he suffers; *"But I would give absolutely anything to have him back."* Father suffers most in the guilt he feels that he did not spend enough time playing with Patrick. *"And that's . . .a lot about guilt. . . .I just feel guilty that I didn't spend more time with him, doing more things with him, because he was so dependent on us. . . .And sometimes after we had done all the physical things that we had to do to meet his needs, I think we overlooked a lot his other needs, which were being addressed when he was at school, when he was with his workers and what-not. But I don't think they were really addressed as much as we should have, from us . . . just playing with him [and] being with him. If we were doing something, we'd always have him nearby and we'd make sure that he had some toys. And he liked to make sure that there was somebody nearby, so we'd put our foot next to him, but we wouldn't really be playing with him. We'd* *be sort of interacting with him, but not playing with him. . . .And that really hurts. I think I could have done a lot better job than that."*

When his own father was dying, Father gave him a message to take to Patrick in the afterlife, when one day they would meet again as brothers. In his message he *"was apologizing for not spending enough time with him."*

Father, too, has few sources of support from family and friends. His extended family lives at the opposite end of the country and he is only able to connect via phone with them. However, he appreciates the support that his own mother is able to supply, even though many miles away. He feels free to call her at any moment day or night. *"I can pick up the phone right now and talk to her about him for an hour."* While his workplace is supportive, its general male tone restricts Father from talking about his loss of Patrick. His network of coworkers is not always aware that he has lost a son, but when they hear this news they most often simply say, *"I'm sorry."* At first, Father questioned how someone who had never known Patrick could be sorry that his child had died, but then he realized, *"They're sorry because [I'm] going through this."*

The couple's need *"to redefine [themselves] as a couple"* is not an easy chore when, before they, *"really didn't have time for each other [Since they] were taking care of the boy."* They are learning that, if they are going to survive as a family, they need to communicate more. They have begun to take part together in activities that remember and honour Patrick, and are striving to engage in other activities that are just fun. As part of Mother's reformulating, she had a need to 'give back' and fulfilled this need by becoming involved in numerous projects in the community. As she did, she encouraged Father to take part in these activities, giving him a way to exit his suffering and to endure his loss. While Father realizes that he and Mother do not talk at great depth about feelings or their most inner thoughts as a way of sharing their grief, he allows her to involve him in her projects-- it serves as a good diversion to his suffering and allows them to mourn and remember, *"We're doing a lot of physical things. And what I think we really need to do, for me, to address everything, is to, maybe, get away from doing a lot of the physical things and just address what's going on in our heads. . . .And, for Mother, she finds it a great therapy, but I don't know if she's just . . . blocking things out, using that as a crutch. . . .I definitely notice that, when I'm busy doing something, mostly at her urging that . . .don't feel sad. . . .And I don't know if that's good or if that's bad or what, (laughs) but I think it almost takes the – it's almost surreal."* One project that has been particularly effective has been starting a web site where Father posts photographs, stories, and poems in remembrance of Patrick. Some days he uses the web site to engage in his loss as he views reminders of Patrick, crying as he does so, *"We're working on Patrick's Website and. . .when we're working on that, it can come over me a couple of times a day. . . .And sometimes we just have to, or I have to, move away from it and just not work on it because we have links to pages that we've written that are very, very emotionally filled."* Other days, he does simple tasks where he does not engage in remembering Patrick, using these tasks to restore an aspect of normalcy to his life. This family actively engages the spirit of their son to make meaning of their loss.

He was the most important thing in my life . . . and still is.

Grieving the loss of their son, and learning to connect in their mourning, in order to survive has not been an easy chore in this first year of bereavement. However, Mother eloquently sums up their process, *"And every day is going to be a challenge. But each of us has courage, and you have to have a lot of courage to get on with our lives without our child."*

So I just kept hanging on"
Creating Space through Loving and Kindness Acts:
The Story of the Smyth Family

The family interview with the Smyth family involved numerous family members including Mother, Father, Brother, Maternal Grandmother, Maternal Aunt, Aunt Choice, and Uncle Choice with Paternal Aunt adding her perspective in an individual interview. It is filled with laughter, jokes, interruption of one family member by another, with all speaking to the fun-loving, risk-taking spirit of Harry. It is also the place, however, where Father sits quietly crying and is supported by other family members when he ventures to share his thoughts on what it has meant for him to lose a son. This family demonstrates the work of families to support one another during bereavement by creating space for individual differences, through kindness and loving acts.

In the individual interviews, each family member relates their own experience of pain during the illness and following the death of Harry. As well, they tell of the roles each family member plays in this process of family bereavement. These roles may be from a distant place, such as Maternal Aunt's role of primarily supporting her sister through phone calls and her nephew through outings, or they may be more involved such as the role of Grandmother who is often present in the home doing tasks and quietly keeping company with family members. As well, Mother, Father and Brother receive the very active support of their "family of choice." Aunt and Uncle Choice have maintained frequent contact in person, and by phone, they encourage involvement of Mother and Father in their social network, and encourage Mother and Father to take trips with them. For the Smyth family, a broad definition of family has allowed them to gain the support needed to cope with the death of Harry.

However, the individual interviews of Mother, Father, and Brother reveal the difficult process of bereavement following the death of a son and brother. Six years later, Father finds it difficult to speak of his loss. He was only willing to do so in an individual interview when he discovered that I too had lost a child-- he then felt that I truly could understand. His interview may reveal some of the difficulties involved for bereaved parents when speaking of their loss to others--the fear of being judged, the lack of vocabulary that allows for inadequate explanation of the experience, or the sense that the death of the child has no meaning and defies understanding. Mother, on the other hand, seems to relate none of these difficulties. She was able to maintain hope while Harry was ill and continues to look for this hope in her bereavement. She tries to inspire Father who seems inconsolable. For Brother, this has created the difficulty of walking a fine line to give support to both his parents. At the time of the interviews, he was aware that his life was on hold, but unsure as to how to change this. As I sat in his individual interview and spoke of this dilemma, he would peer over her shoulder to make sure his parents were not overhearing his words. He believed he needed to protect them. All family members expressed concern for Brother -none had openly discuss this with each other. It seems the participation in the study brought this issue to a head. Brother has now left home with his parents blessing. While it appeared in the family interview that this family had a very open communication style, it seems that perhaps this openness extended just so far. Perhaps their use of humor, evident in the interview, blocked their expression of the more painful aspects of family bereavement. Family is a powerful force in the life of the individual.

Telling the Story: The Spirit of Harry

When the Smyth family gathered to speak of their experiences following Harry's death 6 years ago, they immediately started talking about Harry, the fun-loving "jokester". Grandma and Aunt M related a funny story that occurred when Harry was very ill and in another city for a bone marrow transplant. Aunt M tells the story, *"Grandma and I went to see him one time in [the other city]. And he asked me if I wanted a candy. And I said, 'Well, sure.' But there was only one left. . . .And we were always* *taught if there is only one left not to take it. So I said, 'Mom would you like a candy?' And she said, 'Sure!' And she took the candy. And Harry is looking and thinking, 'Oh no, not Grandma!' [laughter] But she took the candy and was sucking on it and then kinda said, 'Hmm, I'm feeling belchy.' And I'm thinking, 'What's going on?' And Harry was laughing. He had given us a fart candy. [Lots of laughter] What a kid! . . .He was a real comic, that one!"*

Harry's memory brings many reminders of the young man who always kept his sense of humor. Aunt and Uncle Choice contribute another story from the time he was ill. *"Aunt Choice: And I found my poopy animals! [Lots of laughter] Mother: Oh, yeah! When Harry was in the hospital, we had these little animals and it looked like they had poop coming out of them. And people would keep bringing him more. I don't know how many he had of them. Aunt Choice: I don't know either. But I had a whole bunch of them in my drawer. So I took them out. . . .Uncle Choice: But they had a little bit of the discharge problem. [Lots of laughter] They had a bit of a problem containing it. [Lots of laughter] Aunt Choice: So I had to trim them off a bit. [Lots of laughter]"*

Mother agrees that Harry's sense of humor got the family through that very difficult year, but adds how Harry's strength also brought them courage and maintained their hope that Harry would not die. *"And he was always . . .he always talked, joked and talked. And, and that's, in a lot of ways, that's how we'd cope with it, too. We'd do a lot of joking, but Harry was very stoic and he never, he never complained. He never asked, 'Why?' And we were with him 24/7, so it might be different. Father never, I don't think, shared anything, if Harry would have said anything, but you know when I was with him he never. We did things, but we never. . .talked about it. . . .You wanted him to still have hope; but you didn't want to deny that, because we all knew we were going to die. But we just didn't know when. . . .And in my heart, I kept thinking that he was going to be-- that survivor."* She would not let herself think otherwise.

Aunt M. regrets that she had so little time to spend with Harry. *"I didn't get to see him as often as I could have, living out of town [and busy with my own children]."* Just before he became ill, she had the opportunity for special times with him. *"Him (sic) and I, we started having; it was like monthly aunt and nephew days. And what we'd do was, we'd go for lunch and a movie and then supper. And. . .Brother had the same thing, but it was short-lived because it wasn't'; I waited until they were older and my kids were older. And I was able to spend more time with them."* But, through the memories she holds, she knows, *"He'll never be forgotten, because his time here was lots of memories. He left us with lots. Oh, lots – the jokester!"*

While the boys were growing up, Grandma spent lots of time babysitting for Harry and Brother, while Mother and Father were working. She remembers that sometimes Harry could be quite a challenge. *"I would say to Harry, "Time out! You go to the laundry room." But he would say, "No. I'll go to my room." And I would say, "No, no, no, you go to the laundry room." But he would say, "It's no fun in the laundry room!" "It's not meant to be fun!" And he had everything in his room. He had a suitcase full of chips and chocolate bars. He was happy to go to his room. Aunt Choice: And what about the hole between the rooms? Grandma: Oh, that was him and Brother that had the hole between their rooms. Brother: In the closets. [laughter] Uncle Choice: Between the two closets. Brother: Between the two closets, we punched a hole. And then we could talk back and forth through the hole when Grandma sent us to our rooms. [laughter] but of course, that was only one time! Yeah! Grandma: But they would listen when you sent them to time out.They wouldn't sass you or anything, or talk back or anything. If you sent them to bed, they wouldn't necessarily go to sleep or anything."*

Brother contributes more about the challenge that his risk-taking brother could bring to their home *"He had all these people over. And they'd be jumping off the roof onto the trampoline. . .and I'm sitting, sorta shaking my head. [laughter] Great! So that dynamic was: we were equals, but then, at some points, he'd go immature. And I'd have to buck up a bit and say, 'No'" and in different ways around, like I'd go immature and he would buck up and say, 'Come on.' . . . sometimes when I got out of line, he'd come and tell me not to. [laughs] We were both really close, for sure . . . because we were equals."*

Harry was into sports. *"They did lots of sports. In the winter it was hockey, and in the summer it was swimming. So they were going all the time."* It was through the boys' involvement in swimming that the Smyth family met Aunt and Uncle Choice, and their long, close friendship began. *"Well, in the summer, with the swim club and all, it's a lot of family stuff, that's for sure. The swim club in SP was a really neat club. And you were just naturally involved. And on the weekend, it would be going some laces. It was always busy with meets going on, so you were always busy."* But since Harry's death, sports are no longer a big part of family life. Mother says, *"But your [Brother's] heart wasn't in it too much before Harry passed away. And then it just faded away."*

Uncle Choice tells how he and Father have special times to remember. *"We spent a lot of time in the hot tub there, looking up at the stars and stuff and wondering* *why. And then we had discussions. 'Remember when the boys did this?' Or our kids and their kids did something, and Harry is mentioned."*

Aunt P thinks about how life has changed for the family since Harry died. *"They changed because he wasn't there. . . . we usually do something to acknowledge their absence [Harry's and Grandfather's]. Harry's symbol is a star. And sometimes there were star candles; Mother would bring star candles we would light. One time I said a poem at sorta the prayer time before our meal. My mom, for Christmas, decorates the basement with stars. This Christmas, I gave Father and Mother a star . . . light catcher for their window. . . .We'd talk about him. We tried to use humor, because he was a little stinker. And we'd remember some of the things he did and. . .the summer after he. . .it must have been the summer he did die. We were in B.C., which was a big part of our lives. And Harry and Brother spent their summers there, too. And we were there as well, at my family's resort. And my son was at the beach. And later that day, he said, 'Mom, I saw Harry today.' And he was quite matter-of-fact that he saw him and he was there and he was okay. And so [sighs] we spoke of him. [And I said] 'Lucky boy.' I said, 'That's great, you know. He wanted to see you and he came to see you.' And that was great."*

But life without Harry is painful. Father recalls how he felt when Harry got sick. *"I wanted to change places all the time, every day, and I still do."* Mother adds, *"When he passed away, it was like someone cut your heart. You got four pieces. . . .And that piece never comes back. . . .I still give out that part to Harry. . . .[And he] lives on."*

The Family

For the Smyth family, the death of Harry six years ago began a very difficult process of family mourning requiring work on the part of its many members to create space where the pain of loss could be expressed very differently by the various family members, tolerated and accepted through loving acts, and supported through kindness acts. Mother says, *"You walk in a fog, for so long. . . .It still lasts. . . .I don't know if it's a fog or numbness. You know, the disbelief at times; like you just believe he's still. . .here."*

The family interview gave an important glimpse into the working of this family and their very different ways to deal with their loss. Throughout Harry's illness, the family tried to maintain their usual way of functioning. Harry's sense of humor did much to help the family cope and to keep their hope alive. She recalls the day Harry died, *"And when I went into the room, he was just so peaceful. He had a nice smile on his face; so that gave me a lot of comfort, to see the smile. And luckily, they gave us 5 minutes, so I* *crawled into bed with him. And he was still nice and warm. I spent about 15 minutes just. . .hugging him. . . .You had prayed God would take him if we couldn't have a miracle. He was suffering, and so this wasn't meant to be a miracle."* She finds it difficult to see the pain that not only occurred then, but continues for family members especially Father and Brother. She states, *"I think the reason it brings tears is because you know how much everyone else is hurting . . . .But seeing the pain that he was going through . . . .That was the toughest. . . .At the time, too, with him withdrawing, I could see what it was doing to Brother."* She further relates what was happening to Brother, *"Brother was always a talker. He was; he could talk for hours. I could just see him taking on Father's withdrawing. . .He became quiet. And we didn't talk as. . .as openly as we did before. I think it's because he was a protector."*

Mother worked hard to understand the different grieving styles of Father and Brother from her own. Being a nurse and a natural helper, that could mean putting aside her own grief to care for her family. She reports, *"And so I'd try and reason with myself and say, 'No, he's just going through this.' And I kept trying to keep the lines of communication open and saying, 'Well, any time.' . . .And Father chose to withdraw more, so . . . what I did was: he didn't really like sitting down and talking, so I started a journal. I bought a journal for him, and I wrote the first page. And I told him, 'This is how I feel about it. And write down what you feel.'. . . I said, 'It'll probably help.' But I wrote down everything that was making me hurt to see him that way. And that helped. . . .He didn't write in it himself. But I know he keeps it and he reads what I wrote. And I think we were feeling the same, but he was unable to tell me. . . .He didn't write in it himself. But I know he keeps it and he reads what I wrote."* Through this time, Mother had to be patient. She reports of the time she waited for Father to respond, *"Again, looking at the positive, stepping back and saying, 'Okay. What's best?' And, in the long run, what was best for him was best for me, because then he would come out of it. . . .So the way I look at things, if I do what's best for others, in the long run, it's best for me. . . .The frustration lasted a little bit longer, and a lot of times you'd wonder how long it was going to be. And with others saying, 'How can you hang in? You know it's going to destroy you.' And I thought, 'Well, no. If I hang in a little bit longer, it's going to get better, because he knows that he needs. . . .He knows that he needs help with the depression and that.' You know it runs in the family and he was well aware of it. He's very sensitive. And he knew, too. . . .And so, just by hanging in there and letting him know that it was okay to feel this way, and not to get too low, he was able to see through the steps of the depression. . . .And* *he would make angry statements towards you, but I knew in my heart not to take it personally. . . .Sometimes they'd hurt, but you knew you couldn't, you couldn't take it and say he really means it towards me, when I knew that he was angry at a lot of things. . . .And I knew; like I mentioned that I'm stubborn. And I thought, 'No! You know,I went into this marriage and I know he's going through a rough time. And I'm strong now. And maybe, in the long run, I might not be strong; and he'll be the strong one.'"*

Then and now she is most often the family member working to acknowledge the loss and restore family functioning. *"So, after that first day, it was: you tried to do things normally, if that's such a word. And you went and carried on and did things you had to do."* She does this in many different ways. *"And I'll do a lot of reading. And that's why it's a lot easier for me. I'll do a lot of reading; I think that's been therapeutic for me. . . .Going through the process, I could see myself going through the process. And I knew exactly what the stages were the Kubler-Ross sort of thing. But I found that it didn't exactly follow the stages as you learned it. It was much more back-and-forth . . .[one book] really helped me because it tells you all the things that other people have gone through. . . .It just really helps you to realize you're not the only one."* As well, she tries to have a positive outlook, believing in a God who watches over us and leads us through these dark times. She describes it, *"I was never angry. And, to this very day, I'm not angry. We don't really need to ask why, because we know that God has plans for all of us. And you try to think, to reason, not really to reason, but to live. Ah, you know you have periods where you're in a daze, and there's days where I just think he's just out with buddies. . . like he's not gone. . . .Because there's the constant reminders that he's close by spiritually, but not physically. . . .So you never really--you do have up and down days. Like you have days where you miss him. But a lot of the times you're just so busy trying to keep people together and sane. . . .And that's why I did a lot of reading, because that's where I got MY comfort. . . .And I think it really helps because of all the reading you did, and plus with nursing. I think I got a lot of comfort from there because I knew that, I think I mentioned before, the stages that you go through. So you could kind of talk yourself through these things. And that made it a lot easier. I knew God was going to look after things. And [while Harry was sick] I'd explain that it wasn't God that was doing this to Harry, it was something that just was happening. You know some people say that the devil, or whatever. And I'd think, 'Well, you can look at it like that, that an alien has invaded his body. But in the long run, God's going to win because, no matter which way you look at it, we're going win, because either Harry's going to be cured, a miracle will* *happen, or Harry will go to heaven.' So no matter which way. . . .the devil's not going to win."* Mother remains confident that "*God's going to win*" and bring her family through their grief.

However, Mother observed that Father had a different way to deal with his loss. *"[He] was really, really finding it rough. . . .He ended up just; he was just lost. It's not that he didn't want to be part of it. It was just overwhelming for him to make any decisions. At the time, I was thinking a lot of things would be easier for people, but now I'm finding that as I try to protect them, I don't think I could. . . .He didn't want to talk about it. . . .But – that's part of being female and male. Males don't talk about things."* Over the first year relationships became more strained as time went on. Mother reports, *"He was withdrawing. Now he was going through a really rough time. . . .It was like walking on eggshells here because of the emotion and the feelings. . . .He'd have outbursts, like he'd cry and he'd say, 'If I'm making this worse for you, then I will. . .give you up. Like, we'll go our separate ways. But it's not what I want,' I said. . . .I didn't want to hurt him. And then I kept telling myself, 'No, you're not really hurting him. It's what he's going through.' So I just kept hanging on and being stubborn. . . .I was worried, always worried about them and hoping they were able to come to the same comfort level that I was at."*

Reading helped Mother to understand Father's grieving and she realized that even though she too was suffering her own grief, she needed to create a space for Father's way of grieving. She tolerated his difficult behaviours through loving acts that she reports accomplished her goal of keeping her family together. She reports, *"So, it, it brought us closer after he was – because there was no way I was letting go. . . .Because I can see how it drives a spike into relationships. . . .And he's stubborn. But there was no way I was going to lose my family, either."*

She also had to work hard to maintain her nurturing relationship with Brother. She recalls, *"It was hard to let Brother go to [Uncle's]. I remember when that first happened; I could see how people drown their other children, sort of overcompensating for them. And I've got relatives in [the next province]. Well, Father's got relatives and I've got relatives. I knew he would still be looked after."*

Mother is the "*family organizer*", the "*talking head*"-- the one who likes to talk in the otherwise quiet household of Father and Brother. She tells of her work to engage Father and Brother in the work of mourning, while creating space for individual grief. *"And then I'd read something. And then I'd read it out loud to them, no matter if they wanted to hear it or not. I'd say, 'Well, this is interesting.' And at supper time or* *something, I'd say, 'On the way home, I thought of Harry.' . . . And after a while, they started realizing, I think, that it was okay. [At first Father] used to [get angry when she did this], but then he got used to. . .listening to me. I'd gone through quite a few experiences, and he, deep down, he thinks the same way I do, but he was hurting so much that he was closing everybody out. . . .And I just, I would not let him close us out."* Mother also led the way for the restoring of family function. *"We tried to get back to [the usual activities]; that's therapeutic. I go in my garden . . .In my flowers, and I try and do things that I find comforting. . . .[Father] did stained glass and the woodworking. So that was good . . .[Brother] went to [Uncle's] for the summers. But it was hard . . .to let him go. . . .Father and I had decided that we needed to let go also, not to smother him."* For her, seeing the family do these things brought hope that they would survive as a family. *"I could see that he [Father] was starting to get back into those kind of things, so I kinda knew because I was pretty worried for a while. . .because he stopped doing a lot of things."*

Mother also realizes that Harry's death has changed her personally and professionally. As a nurse, *" I've always been told I'm compassionate. So I've had that, but it was more. It was up to a different level. . . .You know when you stated, 'Yes, I can relate.' You knew in your heart you really could relate. . . .You knew what they were going through. "* She is aware that her way of dealing with grief did not always fit with the needs of others. She states, *"I tend to try to bring up things that people don't really want to talk about."* Grandmother, too, recognizes the differing needs for family members, but acknowledges the importance of tolerating Mother's talking when she adds, *"But what might be good therapy for her may not be good therapy for others. Others don't feel the same way she does . . . .But if it makes her feel good, everyone goes ahead with her talking."*

Mother is the one who looks for the presence of Harry in everyday life, often finding it. *"And when we travel, there are certain things that remind me of Harry. Or I see things, like when we were in St. Marten, and you guys were lying on the beach sleeping, and I just happened to get up. And I saw thousands of butterflies, on that little lanai. And you just get this peaceful feeling when you see that. And I just think, 'Thank you'. A little reminder that he's with us. Like the butterflies or when I see rainbows. And I'm sure everyone thinks that when they see rainbows . . .you get this peaceful feeling. Or like when I'm driving back from yogurt, Harry always called yoga that, I'll hear the same song on the radio."* But she also realizes life will never be the same. *"You could tolerate it. I* *think it was just the . . . the loss. When he passed away, it was like someone cut your heart . ."*

Mother is the "*mother hen"* who protected the family during Harry's illness, beginning then to hide her pain from other family members in an effort to spare them. Grandma tells us, *"Well, Mother was acting like a mother hen. . . . I think she tried to protect everybody. . . . Of course, I think you'll hide it from yourself until you can no longer hide it."* Uncle Choice adds, *"And you're always hoping . . .and because Mother shielded us too, because . . .she always knew more than what she was telling. . . .And if there was less hope, than. . .there actually was, she never told us that. . . .And she never told Father that either. . . .I don't know whether it was good or bad, her knowing more than everybody else, for her sake. . . .You have to have big shoulders to have to carry that around."* Mother explains her role this way, *"So, a lot of people don't look at it like that, but I got more comfort knowing that I was needed and . . . I could bring comfort. . . . So, in a way, I was kinda greedy."* For Mother hiding the reality of Harry's illness meant that there was "*always that hope*."

Father is more open in his expression of grief than Mother, describing it as a time of *"uncontrollable despair--just uncontrollable, ah, a black hole, just nothing you could do. Helplessness . . .you kinda wanted to trade places. . . .I kinda broke down more than Mother did. . . .I just shut down. Well, quite frankly, I didn't want to live. . . .I still, some days, it still does; you still think - because the hurt's probably, like I think of him probably the first thing when I wake up in the morning. That's the first thing I think about. . .and then you just get that pain in your heart. . .and that hasn't changed. It's a little; it doesn't happen as often because when you're working it doesn't happen."* Father recognizes that many things trigger his grief and four to five times a day he is tugged from enduring, where he is able to concentrate on his work, into suffering, *"like when Brother will be talking, he'll say something that Harry would always say . . .or something in the house. There's (sic) triggers all over the place. . . .Or if I see some of his buddies around. . .that's a bad one. . . . And see, Mother embraces that part. . . .Where I ran away from that part."*

Soon after Harry's death, Father went through a very difficult period of anger. *"I was angry at God. . . .And I'm still having, I still am. . .I'm angry that . . . we didn't have enough time. . . .But the biggest thing is I'm angry he got it and, and then he passed away."* There was a time where he lashed out at Mother and Brother with harsh words. He reports outbursts where he would, *"Well, I'll bark at Mother or Brother; it will be* *unrelated. . . . Or I'll throw things. . .or if I'm doing something, I'll get really frustrated and then I'll blow up, when I usually wouldn't have done that, as easily."*

Mother tolerated these outbursts and withdrawal periods. In this loving act of tolerating behavior which was not what she knew to be father's true nature. Mother created a space for the expression of father's grief. However, other family members were concerned about his anger and the effects it was have on his family. Aunt P spoke with her brother about his anger, the fears that she had for him, and the damage he was doing his family. Immediately, Father recognized the problem and stopped this behavior and turned to other ways of dealing with the pain he was feeling. He channeled his grief into activity, constructing a dining room table, making stained-glass light catchers of a boy with a baseball cap for each family member, and running. He recalls, *"The physical exertion and just going as hard as you can and that makes you feel better."* His running also led to a number of fund-raising projects in which he and Uncle Choice paired together to raise thousands of dollars for worthy causes such as the Make-a-Wish Foundation. *"So I had this raising money and it kind of got you. . .stimulated that way. . . .You were doing it for your son, for sure. . . .But just physical activity; I've always been athletic, so. . that made me feel better, for sure."*

He, too, performs loving acts, one of which is going to the summer resort where the family spent so much time and Harry had so much fun. But it is difficult for him. "*Quite frankly, I didn't want to go. . . .I just did it for Brother and Mother basically. . . .I don't go down to the lake. . . .But she [Mother] said [I should go]. . . .You do things for your partner, for sure. . .that you don't, particularly, want to do."* He also sees the yearly BBQ, when family and friends gather on the anniversary of Harry's funeral, as something he does for his family, *"I don't need that to remember him."*

Father also found that it was difficult for him to put up with the usual frustrations of his job. *"I didn't care anymore; basically. . .you did your job. And I wouldn't do anything extra, like I used to do in the past. . . .I just did my job and went home."* Through Mother's urging he started into business for himself, a situation he generally finds more manageable but still at times frustrating. *"I'm not as efficient as I used to be. It's frustrating. I'm not as fast as I used to be. . . .Sometimes, for me to make a decision is really hard. . . .I wouldn't say it's back to normal."*

Father struggles with his grief. He gently cried throughout most of the family interview, especially when Mother stated, *"There's never another normal. You can get back to functioning again, but it is not a normal feeling. It's just so hard."* [Father] adds, *"And others don't understand that. . . .They don't go through it. They never . . . they don't understand that it can get you at any time. You can be going along for two weeks and then you're. . .you hide it, but you're right back. And. . .you lost it all right. But it happens all the time. That to me. . .that's what happens to me. I'll be going along good for two months, and then for two days I'll just be toast. No rhyme or reason."* For Father, *"nothing makes sense to me"* about Harry's death. *"When anybody dies, basically [it makes no sense.] When my father passed away, you can see he had health problems. It was slow. And he had, he was 70 some. . . .He went sooner than most, but you know. . . .But you can understand it a little better."*

Brother's grief work has many components. He is not sure exactly what he remembers of the time surrounding Harry's death. *"It was just a big cloud. You're a zombie, pretty much just walking through, getting day to day to day life . . .because I can't remember very much about it. . . .I knew what was going on. . . .[But I didn't want to believe it.] I don't know if I blocked some of it out, because you kind of [get] shots, ah, flashbacks from it. . . .Ah, like say you were walking. . .and all of a sudden. . .you see a picture or little triggers [like a hospital bed or brothers getting along, movies that we saw together]."*

He remembers when Harry was sick. It was a difficult time. *"Dad was on depression pills. Mom was trying to control everything. She tried to stay strong . . .but I had to grow up pretty fast. . . .Because you can't be a 14 year old; you kinda had to boost up your age, mature a bit, protect your parents as well. I feel like I was protecting my parents as well: don't get into trouble. . . Always agree, whatever happens, just,. . . .Be a good kid, pretty much; stay around most of the time. . . .Oh, I cut off from my friends, for sure. . . . You found out who your friends were. But you know some of them were really close before it happened. . . .And then all of a sudden, they'd slowly disappear from your life. I've regained friendship with some of them, but it took a while. . .to gain their trust back and all that. . . .after all what kind of friends desert you when you need them most?"*

When Harry was sick, Brother felt he also had to go out when asked by family friends. *"You're trying to make them happy as well [make them feel like they're helping out] show that they're doing something to help. . .Yeah, you didn't want to be difficult, that's for sure. . . .I REALLY enjoyed my time with everyone that took me in."* But when he went to B.C. he could be himself. *"I visited my uncle, who I have a really strong bond with. . . . And he helped me through that a lot. He'd come and talk to me some nights* *and we'd chat about it and all that. That's when we were first learning about Harry's, ah, what kind of cancer he had, and all that, so. . . .after he died, I just wanted to get away from everything, I didn't want to stay here. I didn't want to - I wanted to be alone, but not totally alone. I wanted to go to B.C. B.C. is my escape. I always wanted to run away to B.C."*

When Brother returned to school in the fall following Harry's death, he found it difficult to tell new acquaintances that he had lost a brother. *"It's weird, because people ask you if you have any siblings, but you really don't want to bring it up, because they go, 'Oh, sorry.' But then, a part of you wants to. It's hard to . . . so when asked I'd say, I'm the only child. . . .Which – well, it depends who it was. If it was just some random person on the street that I didn't think I'd have a long-time relationship with. . . .Then I'd say, "'No, I don't have any siblings.' But then if they knew me, or they were going to know me better, I'd say, 'Yeah. I had a brother'. . . .But after every time I would say that I didn't have any siblings, it hurt a lot, like I was ashamed of him."*

Brother worked hard to manage his grief by himself. *"I would just try to make the best of the situation. I wouldn't really tell them [friends] my feelings or anything like that. I would just try to make everything – I'd keep it inside and then lift up the spirits. And I'd try to fight through it; [and] do something fun. . .get away. Get away. . . .A lot of friends, they saw me down, and they'd [say], "Well, let's go somewhere and we'll go do something, or whatever."* He relied on family members, as well, for support because they were going through grief themselves and could understand. He adds, *"But I found after. . .Harry died, my family, I didn't want to go back to my friends, because my family really turned into my friends. Because I spent so much time with them, and I'd been through so much with them. They were rock solid; we were so close."*

He could see his parents hurting and did not want to burden them, *"but Mother—she knew. . .she knows when everyone's hurting, so she'd come down and sit and talk to you for a bit. You would try to hold the strong front, but all she had to do was reach out and hold you, and I would release all the sadness and agony that was built up inside. And Dad would, too, a bit. Usually it was him that was hurting most. . . .And he really doesn't want; he doesn't really want to talk about it. . . .Seeing my dad suffer was the worst [sic] as watching any parent break down. I really don't remember having talks with my father. My Uncle S. I'm REALLY, really close with him. And it helped a lot. . . .I phoned him every week. . .we still phone."*

But often Brother just took care of himself, *"I don't want to bother people. I don't want to make an inconvenience for them."* He felt, even at only 14 years old, that he had to be *"the strong one, and kinda keep everything together. . . . You just want to be supportive, as well. You gotta be strong."*

In the intervening six years Brother thinks things have become *"more normal"* around the house. *"They're a lot better. . .everything's more livelier (sic) now. . . .We're getting back on track. . . .We're having fun again."* He no longer feels he must be the strong one. For the first time, this summer he will not go to B.C. *"I'm going to get a job, a good one. . . .I need to be distanced, start my own life, [and] kinda re-live; (laughs) try to get back my 14 to whatever. . . .It kinda went on hold. If I didn't lose it, it went on hold a bit. . . . But looking back now, you miss the social aspect of it. . .growing up too fast. I was talking; I was always talking to adults."*

Brother realizes that he needs to grieve *"to release it"* and that everyone deals with grief in their own way. *"Everyone grieves in a different way. Some people run. I run. . . . Some people like to stay around and talk, which is good. I like talking as well. . . .Talking about it is really good. You know you really need to see; you need to share. You can't keep it all in yourself, because you'll just hurt yourself even more."*

To date, his work has been in keeping going, hoping to restore his family to a normal life, even when it meant keeping to his "personal rule . . . to be strong" at all costs. Brother feels at times that he is living in Harry's shadow; so much talk is of all the funny things he did. *"Very much a saint, that's a good way to put it. . . .I'm not living up to that, though."* He also feels ambiguous about moving on with his own life. *"I'm beginning to get a lot of pressure again. You know, like you have to – they're pressuring me to move on, which I want to. But then part of me kinda wants to stay back . . .[to] protect them as well. Which I HAVE to move on. . . .Like, I want to move out. I need my own place. I need a job. I need to experience life. I don't want to be, but it's part of you, kinda has to be. To make them feel good, as well. . .if I'm going to do it. I can only protect my parents for so long. It's not like I'd leave; like you don't phone them or whatever like that. I'll come back and hopefully have that family aspect of it. But I think six or seven years is long enough."*

When his Grandfather died a couple years ago, Brother felt he had not dealt well with Harry's illness and sought to make up for the mistakes he thought he had made, things that he did not know how to handle at the time. *"So I kinda kicked myself about that, but. . .well I needed to unwind. I needed the time off. . . .I needed to escape. . . . It* *was just too much pressure. . . .so with my Grandpa, I re-lived that and I wanted to fix my mistakes."* He spent many days at the hospital with his dying Grandfather. At the funeral he wanted to cry, "*Because I wanted that release; but I just couldn't.*" He does occasionally cry, *"Not as regular as I did back then. . . .Now, if it hits, it's a hard flashback, like if it's not like really a nightmare. I don't have, well, I used to have nightmares, but now I don't any more. It's more, if I dream of Harry, it's like when I told him, when I last talked to him, I said, 'You know, when you come back, don't scare the crap out of me,' because that's what he used to do, right? But I told him this, 'You know what? You don't have to come back and scare the crap out of me; but you can come back when I'm dreaming, and, you know, talk.'. . .I remember my dreams a lot more now than I used to, because I pay more attention. I want to control my dreams.*

Brother has some words of advice for other siblings, "*I'd just tell them to live their life; but don't forget. It's hard. It's hard because you kinda want to live, but you kinda start to forget. But you don't want to forget. . . .It's a hard balance to maintain, for sure."*

But for today, Brother is *"Again, living with, pretty much living FOR my parents, making sure that they're okay, because you don't really want to. I find that if I'm out just for me, it's selfish. . . .but this is not just for my parents; this is for grandparents, aunts and uncles as well. . . .Kinda hindered me in some way that I can't. . . .That I'm kinda stuck in this kinda realm. But I can't escape."*

This is a family that extends well beyond the household to include members not only though blood and legal ties, but by choice as well. It is a family connected through relationships. While it appears that the grief of family members is strongest for those who reside in household, and that Mother, Father, and Brother daily experience the absence that Harry's loss brings to their home, others also feel their pain. Over the years, Grandmother has spent a great deal of time within the household and she continues to do so to lend her support. She tells of her first days of grief when Harry died, "*I'm not an emotional person, but I was just drained. . . .I never cry, or I very seldom ever cry. And I could not stop. . . .But I think mostly because I felt bad for the family, like my daughter and her husband. Especially Father, he had a bad time. It took him a over a year and he, still he; I don't think he's still on medication. But he was on medication for a year because; I mean his boys were his whole life....He just lived for them."*

Grandmother is a strong and constant presence in this family. Mother reports, "*And the other bedroom is the spare bedroom. We call it Grandma's bedroom, when*

Grandma comes to stay." In the family interview, one is able to see that she has a great deal of knowledge of the work family members do together in bereavement. She performs many kindness acts, giving of her time to help keep the house running and family members company. Grandmother saw her role of support as one of being there. *"Well, we just had hugs, so they had to last for a minute. [laughs] But I was always going over there and I would go on days off and spend nights, just to have somebody different in the house because it was very quiet for a while there. . . . Just laugh and joke and play games, watch T.V. with him [Father]. He would just be curled up on that couch downstairs. And he never watched, had much to do with T.V. when the boys were alive. . . .But that was his. . .comfort zone, I think, because he'd be down there. But I'd be there, and if he wanted to talk, fine. I would never push him or anything. . . if he wouldn't want to talk about it."*

Grandmother believes traveling was helpful to the family, *"So then they planned trips and they took Brother different places and it kinda brought Father out of his shell a bit. . . .Just to get away from here."*

She has also maintained a supportive role with Mother and Brother. *"I was there for Brother. Like we'd just do things. He went back to school. I was there for him after school and we'd just be together and plays games, [and] watch T.V. Just nothing special, like I wouldn't be--well, we did go out for dinners sometime. I'd take him to A& W, just to get away."* Grandmother also supports Mother in a number of ways, sometimes acting as her protector if Father and Brother become a bit too harsh with their joking, *"I worry about her because, I mean, Father and Brother, they say things that they think are funny. But like, it hurts; it hurts ME to hear them saying that, "Oh, you're always on our case. You're always doing this. You're always doing that." And you can tell by the look on her face that she's hurt. But, they don't really mean to hurt her. I'll just butt right in when I'm there."* Grandmother does activities with Mother as well. *"We were always together. We'd go shopping. We'd go; she'd have to go for groceries. I'd go with her. We were just together....We never did special things. Well he's at home, so, we didn't have to visit a graveyard. That is good, too, because some people would be there all the time, grieving, I think."*

Grandmother finds comfort having Harry's ashes in the house, *"He was in the bedroom that I was in, so it was kinda nice."* Grandmother is also comforted by dreams of Harry, *"I would dream Harry was in the football field kicking a ball or playing rugby. And always healthy dreams; never sick dreams. . . .He was always healthy. . . .he's in my thoughts a* *lot, but I don't verbalize or anything. Father made these wall [or] window hangings. And it's just a spitting image of him. And he gave it to us for Mothers' Day. And it's so nice in the living room. You just look and there he is."*

Grandmother believes in an afterlife and that belief sustains her, *"I feel like you don't even – I'm in denial. I think I'll be in denial all my life, when it comes to death because I don't accept the fact that it's over. . . .And I'm hoping that some day. . . .The connection's still there. . . .He might not be there in body, but he's in spirit."* Grandfather died in this last year and Grandmother has found that death easier to accept, *"So you know that when you're in your seventies this is going to happen. It could happen. But I don't like it to happen when they're little."*

She has also found that Harry's death has brought her family closer. She believes they have learned to value their relationships and feel the need to pay more attention to them. She adds, *"And I mean you know, we don't know what tomorrow's gonna bring, so you better do it today."*

The family gathers to remember Harry each year at a family BBQ, which Grandmother finds to be a difficult event. She says, "*But, I mean everybody is talking, laughing, joking. And then she [Mother] brings out the music and sets the balloons. . . .They just tear at your heart you know. . . .But it's getting better, it's easier."* She realizes these are value times to remember and for family to be close. She adds, "*And you probably notice that people protect each other. Like I know Uncle Choice is very protective. We kind of protect each other. We're very protective."*

Eight family members were willing to take part in the family interview because mother had asked them to do so. Uncle Choice reports, *"So that's the last thing in the world, which is probably this [the interview] doing this, for Father, is probably the last thing in the world that he wanted to do. . . .Just the way he handles stuff. . . .But it's something, it's tops on Mother's list. . . .even Father said that they thought it would help Brother as well. So, that's why we're doing it."*

Aunts and Uncles too have a role to play in supporting the family through acts of kindness and love. Aunt Choice and Uncle Choice have been an important and constant presence for the Smyth family as they mourn the loss of Harry. Throughout the time that Harry was ill, and continuing on into bereavement, Aunt and Uncle Choice have performed many kindness acts such as picking up the family's favorite food and taking it to them when Harry had a stem cell transplant at a regional center 300 kilometers away. Uncle Choice describes what he felt was his job, *"to see what the family was going* *through, it was painful. We cried with them. We laughed with them. We did whatever. . . just tried to do anything that we could to – you're not going to make it easier, but somehow make it – how are you going to make it more palatable? You're not. You're not going to, but just, just being there I think, was the big thing."*

The couple has also performed loving acts, such as tolerating and accepting the withdrawal of Father while on holidays. Uncle Choice says, *"And it's because I know where he's at. We lost him for 3 days in Australia. He was there. . . .But trying to get 10 words out of him for the 3 days; that was it. It's just something that we knew that, okay, this is what he's gotta go through."* Uncle Choice recognizes Father's need to keep busy. He has assisted Father with his many fund-raising activities and doing other things to keep him going. *"Going to the driving range and just pounding golf balls. . .going fishing with the boys. We took our sons fishing, just getting away. Getting his mind, just trying to get his mind occupied with something else."*

Uncle Choice has noticed the various ways family members cope. *"Mother was quieter about that, but she does more reflecting and thinking about it. And Father tries not to think about it. And Mother likes to think about it. A topic that we would, that maybe I would try to avoid with Father; Mother would want to talk about. But not a lot; I mean she doesn't dwell on it. But she'll. . . .She does a lot of reading and that type of thing. . . .I was always concerned because the two of them are so different in the way they wanted to deal with it, that we would get I'd frustrated at times with, "Why is Mother bringing it up?" or "Why is Father trying to dodge it?" And I told them, "Guys, you're going to have to work together and stuff because your odds aren't good, you know. . . .And they've done very well.*

There were some occasions when Aunt and Uncle Choice felt the need to voice their opinion on the family's functioning, Uncle Choice says, *"I wrote them a couple of letters, as well. . .stuff that you felt that you couldn't say. Well, I put it in words and sent it to them, and always got a positive response. Because you didn't know if you were crossing the line, but it was concerns and it was mostly relationship and that type of thing. . . . Because we were definitely concerned. . . .We had the same concerns, and Aunt Choice, I count on the dear lady, she's tough as nails. And where Father and I would be blubbering, the girls would be holding the fort."* In supporting the Smyth family, Aunt Choice and Uncle Choice noticed, *"It brought us closer together."*

The experience of Harry's death has also had effects on the functioning of Uncle and Aunt Choice, *"we had some good weeping sessions when it was all taking place.*

Mostly when it was taking place, and we could just see what the family was going through. . . .You look at your kids a little – pay a little more attention. . .where your kids say, 'Well, no, I can't make this ballgame or I can't make whatever'. . .Maybe it's just a little more important to make it to that game or dance lesson or whatever it was. . . .We're a pretty close family, anyhow. . . .With our kids and stuff, so I don't think that there was a big [problem]. We discussed it with our kids. . . .We sat down and had some crying sessions because our kids had lost a buddy as well."

After Harry's death, the couple struggled to decide their ongoing place, Uncle Choice reports, *"We were concerned that maybe we were gonna be the last people in the world they were gonna want to see because we were in their face. We were in their face and spent so much time with them prior to Harry passing away. . . . And we were concerned about that. And I thought that we would; seeing us would remind them. . .of that time and maybe they wouldn't want to continue the relationship, or it would be awkward. But it's been far from that. . . .If anything, it's grown and we've done so much stuff together. . . . And the rest; Father and I have got pretty good rapport. We were both born on the 17th of April, so there's something there. . . .There's never, ever been, and I can say some outlandish things, but there's never been a time where he's, 'What do you mean by that?' Never. . . .Or me with him either."*

Aunt Choice found Harry's death particularly difficult, *"I took it hard because of being so close to them, as well. . . .And it was just something that we just never thought that was going to happen. . .so it was rather tough."* She adds about her role, *"We just tried to listen to them and just be a friend. . . .I think the grieving after Harry is almost as secondary as trying to get the living. . .to live."*

Aunt and Uncle Choice did not wait for the family to ask for support but, as Aunt Choice reports, "*We'd just say, 'We're coming over.'"* She acknowledges that their "*core group of friends"* has also provided support, with none of them distancing from the family, "*I think it's been; it's good friendships that we've kept."*

Aunt Choice accompanies Mother to yoga, a particularly meaningful place to remember Harry. They joke, *"Aunt Choice: I remember him when I do yoga. (Laughter) Mother: During yogurt (laughter). Aunt Choice: I don't think he understood the benefit of doing yoga. I think he just thought we were doing it for. . .I don't think he thought it was beneficial."* Her presence allows Mother to continue in an activity that she loves, but might otherwise find too difficult to attend. She, too, worries about the differences she has seen in the grieving of Mother, Father, and Brother. She has been concerned about

Brother, *"I didn't know how Brother was going to make out either. . . . .Falling through the cracks; because I'm sure it's easy enough to do. . . .And I think he still is trying to find himself, a bit, maybe; I do worry about him. I just hope that he's gonna be okay. . . . because it's probably harder on him than. . .Mother and Father in some respects, too. Because he's lost his brother plus a bit of his Mom and Dad, as well. . . .it's gotta be different, that's all.*

Aunt Choice has recognized changes over the 6 years since Harry died. *"I think I said to Uncle Choice about a month ago I thought things. . . .Finally things were back to. . .almost normal. . . .Well, as normal as it's gonna get for them, I think."* She describes reciprocity in the relationship that was seen when she experienced the loss of her father, *"They were very supportive, too, of me, of course when I was going through that. So it was nice."* Uncle Choice sums up the relationship and their willingness to provide support, *"We're just good friends and we didn't do anything more."*

Aunt P was a loving presence for her brother and his family throughout Harry's illness and bereavement. *"You want to acknowledge him, and that he's not there and honor him. But at the same time, you're very afraid of upsetting people. And because Father and Mother were so different in their grieving, Mother wanted to talk about Harry non-stop. I shouldn't say non-stop; that's not true. She wanted to talk about him. . . . And Father couldn't say his name. He just didn't, so, I sorta felt that I needed to do something. And I wanted to honor Father and I wanted to honor Mother. And it was just hard. . .and going through the motions, really. When Mother needs this, and Father needs that. . . .And everybody else is in between."*

Although she, herself, is the mother of two young children, she keeps a constant watch over the Smyth family and is there any time she is called upon, *"You want to help, but you don't want to interfere. . . .And knowing that is a fine line, sometimes . . .I tried to let Father and Mother lead the way. . . .Father got better. He was able to now say Harry's name. It took him probably 2 years. I don't remember exactly. . . .He was becoming more of himself."*

She can speak frankly and directly to her brother and has done so when in his pain he has not seen the toll his behavior is having on his family, *"He was angry all the time. . . .He was incredibly angry – huge anger. It just about tore the family apart, more. Then he started working out, training for a triathlon. . . .And I think that's what saved him, because he started coming back to his old self. . . .And I did say to him one time, 'Father if you're not careful, you're going to lose the family you've got left, because you've gotta* *deal with your anger. You've got to deal with it [now]!' Oh, it's more controlled. I think a lot of it's gone away. . .the anger part. Now of course, it's the grieving still, and the mourning and the loss."*

Aunt P relates that she and Father are not new to hospitals and medical problems. Their father had an aneurism when he was 47 years old that left him with brain damage. Aunt P and Father were at his bedside constantly through his recovery. Later, after Harry died, their father died from lung cancer and once again during his illness Father and Aunt P were called on to be at his side. *"And I thought all families were like that. But now I'm learning that they're not."* But their early experience set the stage for Aunt P to be at her brother's side through his bereavement.

Aunt P, as well, is concerned for Brother, *"I'm very worried about Brother because Brother never cried. He never showed much emotion. He mirrored his mom. . . .And his mom, through the whole thing, was a pillar. . . .She was a pillar of strength. She called the shots. She called the shots in his nursing, kind of. And she called the shots as far as what she was going to let us know. And she protected us. She didn't tell us everything. So that was very difficult because I didn't know the real story. And I could feel she was holding back. . .because she was trying to protect us. But then she was shouldering it all."* But at one point Mother did share the reality of Harry's illness with Aunt P, *"And until I said, "Mother you gotta tell me. Tell me the truth. When he came back from [the city where he went for his transplant], why is he coming back so early?". . . .And she said, 'We need a miracle.' [She adds], So Brother mirrored that. He was going to be strong. He'd never talk about him. He just. . . .They were not even two years apart. They did everything together. They were always together. . . .Harry was kinda hard on him, as a big brother would be, and often is, teased him and stuff like that. . . .So I'm sure he felt some relief, from that. But also, HIS life was totally torn apart, TOTALLY torn apart for so long. . . .And now I see him floundering."*

As well, both Aunt M And Aunt P, provide a constant support and presence for family members. Aunt M states, *"Just to support my sister, my nephew, too, and my brother-in-law. But my sister has always has been so supportive of me; so you try to be there for her all the time."* Aunt M adds about her role with her nephews, *"I was the Aunt who would teach them everything their parents wouldn't tell them."* Aunt M continues to be a major support to Brother, as well as a ready ear for Mother by telephone, *"[We] talk on the phone, more so on the phone. We talked a lot on the phone. We talk. That's, our whole family. . .talks.'*

But, she noticed when she visited the house in the first couple years that the usually busy home had quieted, *"After Harry died, it was really hard. It was like something was missing. It was a great big void. . . .But it's getting better now. Christmas time we're laughing again and. . .it's a lot better."* But sometimes she remains concerned about Father, "*It was like Father looked like he was dealing with it pretty well. And then it's like a build-up again, and it's starting all over again for him."*

Often she is unable to attend the family celebration BBQ but will hear 'his song" on the radio, *"And then, it never failed, like, on that day, seriously, I don't know why, but his song came out "Josh Grobin" and we call it Harry's song. And I think "I don't have to be there anyway, because he's here."* Even when she can't be at the BBQ, she still releases a balloon to remember him on that day.

Aunt M supports her sister, recognizing Mother's need to grieve in her own way, "*Mother hides it well. She really tries to hide it. Every now and then it comes out, like if something's on T.V., then something dealing with death. . . .Then her tears start flowing. So, she tries to be the tough one. . . .I let her be what she wants to be."* Aunt M looks out for her sister. Shortly after Harry died, Aunt M separated from her husband but didn't tell her sister, *"I didn't want her to worry about me because she's just a worry wart, so I'm thinking, "I'll pretend like I'm okay." I didn't want to bring up any more pain for her."*

Aunt M works in an environment where she confronts death regularly and believes, *"All things happen for a purpose in life. And he'll never be forgotten, because his time here was lots of memories. He left us with lots."* She summarizes the family experience when she adds, *"It's like a tooth being pulled. It's like. . .when he died it was; oh, it's a strong hurt. But you, in order to survive, you have to keep going, going on. You just have to. . . .Just always, always think of memories. And then when you think of the memories, and then thinking of him, that he's still here; that's a lot easier, I just find."* She is there helping her "*very close family*" to do just that.

After Harry died, Mother continued to hide her pain, but she agrees with Father who says that to survive you must hid your pain and go on, *"We hide it. We're good at hiding. . . .It seems like some days you just have to put your happy face on."* However, Father adds that while on the outside you try to look okay, in your heart, *"It [the pain of loss] just never leaves you."*

"*God's gotta have a plan*"

Restructuring Family:

The Story of the deJong Family

The story of the deJong family is consistent in both family and individual interviews. Mother and Father tell the story of Hannah's death in their bereavement in a compelling and open manner. While the individual interviews revealed a further depth to the family story, there appeared no need to protect one another from the feelings they expressed. This is a couple that discusses issues openly and frankly with each other and I felt I was invited in to share in a remarkable story of faith and hope.

In almost the first sentence of the family interview I was aware that their belief in God provided a firm foundation for them to draw on in finding the strength to cope with the accidental death of their daughter. Their conversation demonstrates their respect for each other; they can hold very different views (such as the desire for further children) but listen intently to each other and work together to form a family solution.

Mother and Father required different activities to work through their individual grief. Mother shared hers by speaking privately and publicly with others, searching for meaning in the death of Hannah. Father, a quiet man, used outdoor activity to seek ways to remember and create the spirit of Hannah often activity he shared with his surviving daughter.

Family for them is twofold, one themselves and their surviving daughter, and two extended family of blood and legal bonds as well as their church family. This extended family provided many kindness acts that allowed them to get through the first hectic week of funeral preparations and the ongoing months when doing some of the mundane tasks of family seemed impossible. However, Father knew within a couple short weeks that they must work together, as a family, to rebuild their routines and forge a new family where Hannah would have a very active role in their renewed family spirit. It is in the acknowledgment of the need for this process that the couple have turned to their belief in God for strength to restructure their family. They believe that they must continue and find new routines and new ways to be a family with a place within this family for Hannah's purpose to continue to be lived.

Telling the Story: The Spirit of Hannah

It seems that Hannah knew her life on Earth would be short. A couple weeks after her sudden death, mother found one of her favourite books. It was a story that explained heaven to children and on one page when it told how beautiful heaven is, the child in the story asks, "*Can I go there now or do I have to wait?*" The last part of the question had been boldly crossed out. Mother and Father view this as a sign that their exuberant little girl, so full of life, had sent to help them understand that she knew she was on earth just for a short time.

Hannah was an outdoors girl. Happiest when she could play outside in the dirt with trucks-- no dolls for her! Father recalls, *"Hannah was a truck kid, right? And I remember even in the basement, when we moved to this place out here, it was just an open lot. And, so we had the walls up and we were pouring sand in. And when we were spreading it around, we saw a salamander (laughs) about this big. And we're poking it with a shovel. Hannah just goes, grabs it, drives it around like a car [laughter] 'Vroom, vroom.'* He adds, *Whenever kids come and play with the frogs, I always immediately think of Hannah. There's some things I just kinda connect with her. And when the frogs come out. . .because we have tons of frogs, and I always remember Hannah then because she would collect the frogs. . .There's thousands of frogs around here and she just LOVED catching them."*

Hannah was a bright, talkative, adventurous tomboy who always *"had a desire to figure things out. . . .[She was always] going out and trying stuff out . . . a very quick learner."* Hannah was the child who brought activity and fun to their household. Her younger sister was a much quieter child who preferred playing with dolls to Hannah's trucks. Hannah was the leader when it came to the two of them and their activities. Mother says, *"She was a vibrant kid who really filled our house. . . .This was one of those kids who you just didn't miss."* Sister was lost when Hannah died. Mother says, *"She had a really rough time in the fall after, so it would have been 6 months after Hannah died. She had a really rough . . . few months there, where she with withdrew from all of her friends, even kids that she loved to play with, she just wouldn't. And we had troubles with her participating in anything. At Sunday School, sometimes she would just lay down on the floor and just refuse to participate in anything".*

But Sister loves to watch the family videos that remind her of the fun she had with her older sister. She can spend hours doing this, talking to mother and father afterwards about all those fond memories of the sister she truly loved.

Mother adds how Father and Hannah were always busy outside, "*Father and Hannah would spend hours together walking, canoeing, and watching sports. She was tomboyish."* Father adds, *"We enjoyed doing [things] together. . . .[and now] I need a* *hockey pal. . . .She loved going on walks, and we went for lots of walks with her. And [now] kinda just going around out back there, where we walked with her, brought back kind of happy memories. . . .This is a comfortable place . . . .[But] everything just becomes a little. . .less active [without her]."*

The Family

The story of the deJong family tells of a remarkable determination by this young couple to find meaning in the sudden-death of their five-year-old daughter Hannah. Father states, "*I mean, we came back and we're just kinda sitting at home. And it just feels totally, like a foreign place, almost. . . .And then, we tried to sleep that night; and I couldn't sleep at all. . . .And the next morning we were both. We ended up being here when the sun came up. And I remember that, just kind of sitting there thinking, "Yeah. She's not; here with us." That was just a really, a weird feeling and just knowing that that she wasn't gonna, gonna be there. . . That was really hard, just to know that. You're sitting here and the sun's coming up again, you know. . . .And I'm sitting there thinking, 'It's totally different now."*

When Hannah died in a playground accident, they went from a family with four young children to a family with one child. Hannah was playing outside with Sister and the family's two foster children when the accident occurred. Mother had just popped into the house to start supper. Unfortunately, the youngsters all saw what happened as Mother struggled to revive Hannah, performing CPR as she had just been recertified to do. Mother still worries about the effects viewing this tragedy had on the children. She adds, *It made my heart ache, when Sister would tell me the details."* Not only did the family lose Hannah, but they also asked that the two foster children in their care at the time be taken to another home where their needs could be met in a nurturing atmosphere that did not include the mourning in which their own family now found itself. Mother speaks of the children's move, *"The people that they stayed with have counseling backgrounds, so they were able to work through a lot of that stuff with them."*

Father was not at home when Hannah died. He states, *"I didn't really know for sure, like Mother said she was pretty sure. But, when I was driving home, after she had told me . . . .I hadn't had the details or anything, so I was still hoping for the best. . . .But, in the hospital, we found out. And just the initial part, I was kinda ready for it because Mother had kind of talked about it on the way, that, she didn't think there was much of a chance for Hannah to make it. . . .I was still hoping until we actually got there. . . .And* *even driving home from the hospital, it was kind of weird. Like to fill up with gas and it was just like everything just seems to be carrying on."* But as the couple was driven by a friend to the hospital, Mother put away her own immediate pain in the knowledge that her daughter was dead and focused on praying for strength for Father who was still hopeful that Hannah would survive. Mother recalls, *"Father was praying that she would be okay, but I already knew she was gone."*

Arriving at the hospital and being ushered into a small room, Father clearly understood that his daughter had died. Never did he resort to blame Mother, who was present at the accident scene, but trusted that every care had been given to keep her safe. Father says, *"The only thing I was worried about was that she would feel guilty because she was the one who was here when it happened. And so I tried never to be accusing or anything like that because it just; she's been alone for 15 minutes on all kinds of occasions. . . .But that was one of the things that I thought might come up and I didn't want that to. . .because if you're the one in charge. . . .I think you're just going to feel that way and. . . .Just to make sure that she knows that. . .it's something that just happens."* The family philosophy was one of creating opportunities for children to explore their environment and for Hannah, explore she did.

When the couple was allowed in to see their daughter, Hannah was still attached to the tubes and machines that the doctors had used in an attempt to resuscitate her. Mother and Father were allowed to hold her, but only when the nurses passed her lifeless body from one to the other due to the requirements of the medical examination that the law required in all unexplained deaths. It was at that moment that the young couple decided that, *"We want to seize whatever opportunities God gave us out of the circumstances. [For mother this would mean] opportunities to really connect with people that you don't get every day."*

After completing hospital forms and calling their parents to confirm that Hannah had died, they were driven home by a friend. They had alerted them to the possibility when they had phoned on the way into the city to tell them of the accident. Both sets of grandparents immediately made arrangements to come to be with their children and surviving granddaughter. Father recalls, *"But they were here, basically as soon as they could get on a plane. . . .Mother's parents and my parents were both out. My brother took a little [time]. . .so both of our parents were out, as quick as they could come, pretty much. . . .And that was good, too."*

On returning home, they learned that their church community had already been busy bringing in motor homes to their acreage property so that the couple's parents and siblings could stay close by and lend support. Father says, *"Within a day, they had four fifth wheels, for all our family coming in, to stay in. . . .So we were all able to stay kinda together right here, which was really kinda nice. . . .we were all here; they didn't have to get hotels and drive back and forth or anything."* From that evening and for many days to come their house would become an environment of support, a nest that allowed for the beginning of family mourning. Mother reports, *"I found that after the first week was really quite crazy. I mean there was stuff going on that whole week and people; and it was almost overwhelming. . . .When that kind of died down a little bit . . . that's when you really have time to really think things through and so the questions become much more prominent after that."* The next day both sets of grandparents arrived and immediately the stories of Hannah, the tears, and the laughter began. Mother recalls, *"We definitely had a lot of people who were taking care of us, in different ways, practical ways. But, there was also a sense, at times, that we were taking care of other people. And people would come and they just didn't know what to say or how to respond. And they'd just kinda lose it a little bit; and they'd start crying. And so there were some times where I felt like we almost were in a spot where we had to comfort other people, too. . . .We had spent so many hours just working through it in that first week. . . .I think because we were here, and we were just, for the whole first week we were just together. People take turns grieving. . . .And so it was kinda like, okay, for this moment, this person's having a rough time with it. And then it would be kinda mutual there."* Father adds, *"Very much so; they were both very, very good. And we're fortunate that way in that, we both get along with both sets of our parents. . . .And you really notice it at a time like that. . . .When they're both able to come and just stay here together. . . .And we get along with each of them. And they get along fine with each other. And then you're not focusing on other stuff. You can then just totally think about what's going on. . . .That worked out really, really nice. . . . Where you could walk in here and you wouldn't know who, it could be any two people sitting down. . . .You could just walk in, and join them. . .and you wouldn't feel. . .you were interrupting or anything. . . .It was very good that way. . . .We just, didn't have to worry about any conflicts or anything like that."*

While it took a few more days for Mother's brother and sister-in-law and father's brother and his wife to arrive, an atmosphere of support was unfolding. When paternal Uncle arrived, he remarked to Father on the sense of peace he felt in coming into 'the nest'. Father says, *"They felt horrible before they [siblings] came; and then just sitting around in this group, they actually. . .it felt much more; they felt much more at peace."* Mother adds, *"We were sitting around just talking; there was moments of grief and mourning. That was definitely part of it, too, but peace in the midst of that, which seems kinda contradictory. But I think the two can exist together. . .because we feel so strongly about faith in God. . . .And so, definitely, we had a peace that she was with God."* The stories that were told began the process of creating a spirit of Hannah-- a spirit of the *"funny kid, [who could] get into some real mischief. . .because she was very determined to do something."*

Over the week that the entire family and many friends were engaged in planning her memorial service, Mother and Father came to appreciate, *"other people's experience and how they [felt] . . .she affected their lives."* The nest created a space for the family to share many stories and construct the spirit of Hannah. Mother recalls, *"Sometimes people would say things and it would just be so funny, and we would just laugh. I mean, I think we needed that. And then we'd have a good laugh. And then we would start crying again."* Some ladies from the church created a scrapbook from the many photos that were being shared. As well, they created a poster collage of Hannah's many looks and expressions from the family's photos. These memory items have continued to be cherished by Mother and Father. Further, the couple performed a loving act to the community when they allowed TV interviews to take place in the midst of their pain. TV *"aired some really interesting things. . .that normally wouldn't be acceptable"* but that week the TV did air the story of Hannah's spirit. The couple spoke of Hannah's death publicly because they wanted to let others know that, *"God's gotta have a, plan . . . if that is Hannah's purpose, whatever it is . . . to open the doors or whatever . . . that we would follow."*

On the Saturday of her memorial service, many people took part in the preparations and in conducting the service. Dad is a teacher and many of his students came to read a special prayer, share a poem they had written, or sing a song. The church community had decorated the community hall where the service took place and did all the work of preparing a luncheon for the many mourners who were in attendance. Father's sister was too ill to travel the long-distance to be with the family, but she prepared a special reading to remember her young niece. Father recalls, *"It was some relief when the memorial was done. You're kinda not really looking forward to it. It's just gotta happen and you gotta go through it. I was quite happy and kinda, 'Okay, that's* *done. Now we can kinda carry on.' I think that was, for me, that was kind of a relief and just a time to sit back and just, 'Okay, we can just kind of do nothing."* Mother was somewhat surprised to find that she enjoyed the presence of so many people in her home in her first week of grief. *"I guess I would have thought that I would have responded differently; that I would have maybe, wanted to be in solitude more. . .because, generally, I do withdraw more when I'm in pain or something . . . .But at the same time, it was different. That's how I found it, because when we had tons of people in here, and we were just sitting around talking. But it felt really healing to actually talk, and hear other people talk, about memories of Hannah."*

Directly following the memorial service, the aunts and uncles had to return home, but all four grandparents stayed on to continue the work of supporting this young couple and their surviving child. Father recalls, *"All the way through, even they would, just asking us, you know, 'How long do you want us to stay?' And they would have stayed longer. They would have left earlier. . . . They just said, 'When do you want us to go? Okay. That'll be it.' . . . And so that was really nice for us, too, that they didn't. There was nothing pushed on us, and we totally felt that they wouldn't be offended when we asked them to leave. . . . And they wouldn't mind staying. And they made that clear to us."* The tears, the laughter, and the photos and stories of Hannah continued to be shared by Mother and Father, grandparents, and the continuing stream of visitors to the household. There were breaks i to eat meals together, food prepared by the church community who had brought in an additional refrigerator to hold it all. The couple took walks with sister on their acreage property, just the three of them, creating a private space and solitude for their grief. These walks were quiet times of private reflection with few words being shared between the couple. They began to get a sense of what it was like to be a family of three. Father remembers, *"It's kinda hard to soak in. You don't really know what's going to happen. . . .And that there's all kinds of questions, like: what, who are we going to be as a family now? Where are we going to head now, how are we going to, how are we going to deal with not having her around any more? Like how is it going to be? [It's] going to be different, because you know it's going to be different and you can't imagine what it's going to be like. And it's hard to think at that time, kinda looking ahead and thinking, 'What are we going to do as our family now? And who are we going to be?' Because you kinda know who you are, and you know that it's not going to be like that any more. . . .And just at that point, thinking, 'I have no idea.'"* Father remembers that those thoughts came very quickly. He adds, *"Not in the first few days. . .*

.The first few days was just, probably more shock than anything else . . . .At first you're trying to understand why. . .why it happens. . . .And eventually, you just say, 'You're never going to know why.' And then you just kinda give up on that one. But the first few days was really. That was one of the questions that you just. . .keep thinking about."

At the end of the second week, Father decided it was time *"we kind had to carry on again."* Their open relationship with their parents and the positive relationship shared between the two sets of grandparents allowed them to be very direct in stating their need for space. Following the exit of the grandparents, the young family began to adjust. Father says, *"At first, it's kind of a lonely feeling, even though there's lots of people around. . . .But you feel that, at least my relationship with Hannah is. . .done for now, that it's not going to be building up like it was. . . .At the same time, you really feel part of a community because [town they live in], our Church family, people at school, my students even, really came together and supported us. . .So you kind of have the kinda two opposites coming together at the same time. And I just kinda remember that often kinda not knowing which way to feel, or even floating back between them. . . .Where, one day you just wake up and you're just; you feel all alone. And the next day I'd feel; we get these cards from whoever, right, and we'd read them and you kinda feel there's a lot of support. And so I would kinda feel supported in that way. . . .And it would flip back and forth."*

But before they started on this new routine, Father, who had been told by his employer to *"take all the time he needed"* decided that he needed to return to school for one last visit with the graduating class. He put aside his own pain to hold a *"mourning class"* to *"kind of explain what had happened and where we were,"* and give the young people the opportunity to ask questions and express their thoughts. The loving acts performed by one family member to another and extending into the community even extended from a child not quite four years old. For on this day Mother found, *"It was hard having [Father?] gone. . .I would cry. . . .But sister, but she's a real nurturing kind of kid, she understands how people are feeling and kind it just seems to be good at that. And so she would come over and she'd hug me. And I remember . . .I was laying on the couch and she came and crawled on top of me and just started crying with me."*

Summer was "*much quieter*" than they had experienced before. They did not have the motivation to organize the usual family camping trip. Father remembers, *"I think the first year, we just couldn't; we didn't bother planning. You have to plan for these things, and we just didn't feel like planning for it. . . .And we just couldn't be bothered at* *that point, to make plans. . . .I don't know if it was the energy, or just more the desire to do anything. . . .I think if I wanted to do stuff, I would have had the energy for it. . . .But I just didn't have the desire to go out and do stuff. . . .I just kinda felt like being quiet and sitting around at home."* They stayed at home taking walks, playing quiet games with their remaining child, talking to each other about Hannah, laughing and crying, together and by themselves. Mother's willingness to talk was helpful to Father. He says, *"I just think just being open to talking is probably the biggest one. . .that we were just able to. And getting so much time off of work helped as well. . . .We had three months that where, we could just sit down and talk to each other. . . .And just kind of talking about that, it gives a little comfort."* In the quiet of their home, the family of three continued to create a space for the grief of each member. Father recognized that his walks alone took on different aspects than when he walked the same paths with Mother and Sister. He says, *"Because when I would go around by myself, then there was more just, there was a lot more thinking, less talking. Just . . .kinda contemplating what is happening? And I'm not sure, how different it would be just being on your own, just allowed me to kinda just be quiet. . . .And just think, or whatever ended up happening."*

When fall came and Father had to return to school, he found the first days very difficult. Father recalls, *"Returning to work was difficult. That was really hard. I still remember the first . . .meeting. And I was just; I broke down and cried there. It was just; it was really hard going back and just kinda starting to carry on again, where this is going to be part of my routine now without Hannah. . . .And I had a lot of support. . . .But it was still really, really hard. . . .It's another one of those steps that you have to get over. . .just the idea that you're just going to be carrying on into a normal routine now. . . .Which I was kinda looking forward to, because if I, we wanted to kinda get back to normal. . . . But to actually go to school and teach that first day. . . .It was just really hard. . . .It started and oh, this is life. . . .This is what it's going to be like. . . .It's kinda knowing that that time we had to be together or to mourn together, was going to change. . . .It wasn't going to be like that any more."* Mother and especially Sister were also finding the absence of another family member extremely difficult. Mother signed up Sister for many activities in hope of keeping her busy and her mind off of her loss. She set up a schoolroom in Hannah's room and held daily learning sessions for Sister. But this plan did not work. Sister began to withdraw, refusing to take part in activities or play with other children. *"She had a really rough time"* and needed to remain close to her parents, moving from the room she had occupied beside Hannah's to one beside Mother and

Father. After these behaviors continued for several months, the couple decided to seek counseling for Sister. *"She had to kinda find her own way"* and slowly did, becoming an independent, quiet little girl by the time she started to kindergarten the following year.

As Sister was adjusting to Hannah's loss, so were Mother and Father. For Mother, it involved sharing with others and living and Hannah's purpose. She says, *"I really felt like there were opportunities to really connect with people that you don't get every day. . .for instance, in being a grieving mother. . .when you open up to people . . .are kind of vulnerable in front of people. . .they are; they just seem more comfortable to talk to you as well. I just found that when I'm sharing . . .some of [my] pain, I think other people feel free to share their pain. . . .You can actually connect with people on a deeper level than what you'd normally would be able to . . . and talk about meaningful things."* Mother discovered that sharing lessened her pain and gave others the opportunity to lessen theirs. Mother continued to meet with people throughout the first year of her bereavement on almost a daily basis. Mother believes, *"My biggest thing, I think, in relationships right now, is to get, to have depth, and not just to spend so much time talking about menial things. . . .That's part of life, too, and so that comes into conversations too. . . .But to really share who you are with people and to be vulnerable. . . .Because, it's easy to kind of put up the wall and just keep people at arm's length, or whatever. . . .And I think now, that I've experienced Hannah's death, to me it just; I see that there's value in life beyond just the little things. Like, there's meaning in life and just, I guess, in my conversations with people I try to really talk about things that matter."* When the second year came she was ready to speak publicly to groups about the meaning she has found in the life and death of her daughter, something that before she would not have thought herself capable of doing. Each time mother prepares for these speaking engagements, she actively mourns the death of Hannah once more, spending the day before crying. And when she writes her speech, she says, *"I've actually found, when I've been preparing to speak, that's when I have probably the most mourning. (sighs) I always find the day before, especially, I cry pretty much the whole day. . . .But it's working through it. It's all the details again and it gets all brought up again, fresh and new. . .each time, and so that's a very, very solitary thing, for sure."*

Father, too, finds that his experience of loss has changed him. He cries more easily at any emotional experience and finds that Hannah's death *"draws out more of who you are. . . .The loss of Hannah is going to become part of who you are. . . .This is part of who I am now. Like I'm different because [Hannah lived and died]."*

Despite the pain and sorrow of losing Hannah, the family has learned to cope with their loss. A large part of their coping is rooted in their belief in God. Mother says, *"God is a big part of our lives, as much as it is for us. . . . He's part of our lives."* Father adds, *"I believe that there was a purpose or a reason why she died. . .I want to kind of give purpose to her life. . . . I still believe that God is in control of everything. . . .And that He allowed it to happen, for whatever reason. . .that He chose. . . .And even though, to me, it doesn't seem to make any sense that: why would someone who's in control let this happen. . . .If God came and told me that that was the reason that Hannah died, well I wouldn't like that reason at all. And that's one of the things I thought, you just can't. . . you just have to trust that. You know you have to decide: 'Is God in control or not?' And it's kind of a choice you have to make. . . .And for me, that was the choice; and I decided 'Yes, He is.' And I have no idea why He did this, or what His plan is, or anything like that. . . .But the idea that I CLING to is that He is in control and His purposes will work out through it. . . .Right now it's; you don't know and I think if I knew I don't know that it would make it any easier. . . .There's moments where you just think that it just. . . . 'Why, why would You give us this great girl . . . and then take her away so soon?' And then, if you think about that, and you think about our answers that the time that we had with her, I wouldn't trade that for not having her. . . .But it's a choice thing again. . .you have to decide. You can be angry or you can accept what's happened. And I think there's nothing wrong with questioning. . . .And even though you know the answers aren't going to come, and even if they do, it doesn't make any difference. I'm just saying to God, 'You'd better make it worthwhile. You'd better use us to reach other people, or whatever You're going to. . . . I do want to know that other people have been touched by it and have had their lives changed.' . . . And I think that if that doesn't happen, it better not be for nothing that it happened. . . .But, somehow, the world has changed because of her."*

Just as Father has many questions, so does Mother. She tells of some of hers, *"What do I do with this situation that I'm in? How can this strengthen me? How can I grow through this? How can I move on, not, I guess, forgetting Hannah or the experience, but to move on with life, for sure? Those are kind of questions that I CAN find answers to. . . .So, I'm kinda finding that those are better questions for me to ask. . .Some are still open-ended. . . .But I think a lot of them have to do with me, and how I respond to. . . there's nothing that you can do to change what's happened. . . .So, it comes down to: How do I respond? And so, a lot of it is really hinging on me. . .and what I do with it. [She adds], I've kinda come to understand that sometimes it's the question* *that needs to be changed because some questions you ask, and you don't get the answers to. . . .And so, I've kinda determined that maybe I need to start asking different questions, the questions that you can get answers to. . . .So, some of those why questions are still in the back of my mind. . . .But I know that I will probably never have the answers to them, so I've moved on to new ones, I guess, that hold more promise for answers."*

Father further reports that that his faith leads to choices in mourning. He says, *"And I think I feel that I have to kinda . . . choose, 'Am I gonna kinda just deal with what's happened . . . and kind of just make the best of it and carry on and figure out well, how do we use her death?' In some way I feel a little responsibility there that this might be an opportunity that God has given us, as well, to talk to other people and, because we've met a lot of people now, who, we've heard, have lost kids, too, that we never knew about before. Some of the people we knew and some we didn't. . . .But, in that way, we have some opportunity and I kinda feel it's my responsibility to work with Mother and that, too, to kinda reach out to these people. . . .And in that way, the memory of Hannah will carry on, too."*

The second year of bereavement was different than the first for the deJong family. *"Somebody actually told me, early on, the sooner you can do the first, the better it is."* After the first year of quiet, when each 'first' was so painful, living has returned for them. Father says, *"We're kinda getting used to just having Sister. . . .But when I think back to how it was before, I really miss those times. . .and I, it's easier now because we're farther away and it's just; it's been two years of just Sister now. . . .And so, that's kinda become more normal. . . .And we're just used to: that's the way it is now."*

They did not celebrate Hannah's birthday this year. Their Christmas carried on as it did when Hannah was alive. They remembered her on the anniversary of her death by planting a tree-- a tradition started by the grandparents after the funeral and continued on the following year. But this year they were able to have friends join them with the tree planting. It did not have to be quiet private remembrance of the first year.

Mother has started to renovate bedrooms as they prepare for other children. The couple has decided that they will foster to adopt and also attempt to have another child oftheir own. Father tells of the couple's decision to foster to adopt, *"Now we've kinda decided that, this is where our family is going to head now. And we'll see what comes our way in fostering. . . .And, if that ends up being adopting. . . .I mean we'd love to have other kids. I love having kids around. . . .I miss that part, kind of the noise of kids.*

(laughs) Because Hannah was really that way; and Sister is, can be noisy at times. But, by nature, she's a quieter kid. . . .And so, and with just only one, it's tough for her, too. . . . I know she'd love to have other kids around. And we never wanted to have one child, to have an only child, like right from even before Hannah; we never wanted to only have one. It was always two or three or whatever, but never one. . . .And now we're kind of in a situation where we're at one again. And we don't want to keep it at one."

This has been a difficult decision, especially for Mother. She reports, *"The big question that we've teetered on, and I think we've come to an agreement on now, is what to do about further children…You know that was a big one for us that we battled (laughs) a little bit. Just struggling with what the future held, but, but for sure, most decisions, I think, have been unanimous."* She felt that their plans for a family were complete before Hannah died. The need to revisit these plans sparked some of the only bit of anger that she has felt during bereavement. Father adds, *"We thought we were done. And now we have to figure out where we are going to go from here and . . . sometimes that's a little tough. . . .How old can you be before you're too old to have more kids? You really don't want to talk about it, and really don't think you should have to, but you do."*

Fortunately, this couple has always had the ability to talk about difficult matters, to negotiate, and come to an agreement that is acceptable to both of them. Mother reports, *"I think we're fairly similar, I would say I think both of us have found it really helpful to talk about Hannah. . . .So, that lends itself to being able to grieve together."* The deJong's have learned, as Father reports, *"Sometimes we like to think that we can plan our life, can't we? And then something like this happens and you realize, 'No. We don't plan it.'. . . We were talking about how we have our plans for this. And Mother has this 5 year plan for what we're going to build here. [laughter] And you just think, 'Yeah. That might happen.' I'm very aware of what could happen or could not happen. [It changes how you live] in some ways. Some of the, not in what I do, but just the attitude that I do it with . . . .The idea that, I want to make sure that I'm doing things for the right reasons."*

Their work as a family, within their environment of community support, has led them to restructure their family and accept that this is, *"how things are now. . . . and you just kind of have to accept that it's not going to go back to how it was before. This is who we are now."*

"There was definitely a oneness in our grieving"
Time to Work at Creating a Restructured Family:
The Story of the Schmidt Family

The story of the Schmidt family reveals the process of family bereavement over time. It has been 10 years since Mateo died suddenly. In the family interview attended by Mother, Father, and Sister 2 (Sister was at work and unable to attend family interview but added to the family story by way of an individual interview) the work the family did to cope with the death of Mateo was discussed openly and with emotion by Mother and Father. Sister 2 had little to offer in the family interview but sat listening intently to a story that she had obviously heard many times before; she did not seem distressed when her parents would cry.

In her individual interview, Sister 2 was able to provide a clear picture of her own developmental process of bereavement, including her striving to make meaning in the membership of her brother in their family and the support she received from family members during this time. When Sister 1 was interviewed, she too could articulate clearly how making meaning of Mateo's life and death and in particular, the role the family's belief system had in this process, aided her own work during bereavement.

From Mother and Father Schmidt the family interview revealed their ability to talk openly and frankly of their feelings. They added to each other's story constructing a coherent account of how they've moved over time from a bereaved family whose first years were very painful reminders of the loss of their son to their later years where they have been able to continue to speak of Mateo in their family and in the community. They relate that while they still have moments where they can acutely feel the pain of loss of their son, for the most part they're family is now restructured into one that is "all girl." Father relates how he misses the opportunity to mentor a boy, but how his girls feel his life with delight. Their faith in God allows them the belief that they one day will be reunited with the son who brought so much joy to that life.

Telling the Story: The Spirit of Mateo

When Mateo died 10 years ago after being hit by a car, Mother recognized immediately that the sweet lively little boy that she knew had been taken from her and that only his body remained on this earth. Entering the room she saw the respirator attached to the small boy and as she approached the bed she noted that his eyes were slightly opened. Mother recalls, *"He looked really good. Now his eye color was* *completely different. He had grey-blue eyes. And that's one thing, his eyes weren't completely shut, and I noticed that his eyes were more of a hazel. And that's just not; my son doesn't have hazel eyes!"*

But his spirit lives on in the family. Mother said, "*I still talk about him and . . .actually one of my neighbors, I was talking about Mateo. And she knew my two girls because my two girls went to school with (her kids). So she says, 'So, by the way, who, where is this son of yours that I always hear you talking about?' And I said, 'Oh, he died a few years ago.' She goes, 'Oh!'"* Father reports that he too frequently speaks of Mateo. "*It's always a joy for us to talk about him, and even today. . . .He was my firstborn. He was also my son, that I was so proud of, and had so many dreams…just of working with him and of teaching him and of seeing him, whatever he did for his life, seeing that. . . .Seeing that come to pass and happen. . . .It's a whole different (thing) with daughters. . . .It kinda changed you, as such, as a parent."* The family keeps a collage of pictures up in the hallway and has a memory box filled with special items like, "*His shark gloves. When I was in France, I picked up these second-hand shark gloves. They look like sharks. . . . And he used to run after the other kids at school, especially the girls and scare them with these shark gloves. So we kept that*". Together with the family videos, these items have been very useful in keeping Mateo's spirit alive in the family. This has been especially important to Sister 2, who was only 2 years old when he died. Through the years she has relied on these and the stories her family tells of Mateo to understand her family and what it means to have a big brother. She says, "*Well we have a bunch of videos and I watch them. . . .So I sort of get his personality from that. . . .I think, if I didn't have any videos, or anything and I saw a picture of Mateo, and I didn't know what he looked like, I would know that was my brother, because, like being with him, I think I would recognize him as my brother."*

Mother adds, "*He's a memory that we all keep. . .He is definitely still (with us). . . . he's my firstborn. . . . When you have a kid on your hip for all those months. . . .And I think, at first, they think they're an extension; you're an extension of them. . . .You think you're laying your head on your kid's head; so you feel back, and you realized he's really laying his head on you that type of thing. . . .He's part of you*".

The Family

Ten years ago Mateo, the eldest child and only son of the Schmidt family was hit and killed by a car driven by an 18-year-old woman. Over the years, their grief as individuals and as a family has changed, in large part they feel because of their ability to openly talk about Mateo, watch family videos that help them remember, and trust in God to guide them through. Father states, "*The more you talk about it, it's a healing thing. . . . That's one thing because it was one of the things that helped me the most. It was healing . . .don't, keep it inside. . . It helps not only us; it's a healing thing, too, to talk about your loved ones. . . .it's helpful not only to ourselves. . . .But it's also helpful to others who know him, who know us, because they feel comfortable (to talk about him).*"

But Father also recognizes that there are moments of pain that continue to live in your heart. For him, this has been the regret that he could not save him. He says, "*What I dealt with a lot was the instant that he was hit by the car. . . .How I would have loved to save him that, just the pain. . . .I mean, of course, it happens like that (snap). He's gone, but still just the thought of It . . .that tormented me. . . .I wished I could have somehow been there to spare him that moment of terror. . . .Like just that fraction of a second, of just terror, it would have been.*" Through many loving acts, family members have been there for one another, supporting each other even in moments when their own grief needed to be put on hold to do so.

The Schmidt family was on a two-week holiday to the southern United States to visit Mother's family when the accident occurred on the 11th day of their journey. Earlier that day, Mother, Father, Mateo, five-year-old Sister 1, and two-year-old Sister 2 had returned from an enjoyable day at the beach. They were having a delightful holiday especially since Father had been working long hours before the break causing Mateo to comment, Father: *"And Mateo even commented on [it]. 'We don't see Dad'"*. Mother: *"[He said] 'Dad is like a good friend that we know very well'."*

At the time of the accident, Mateo was in the care of his paternal grandparents and uncle. They had gone out to the city outskirts to view the Hale-Bopp comet as it traveled across the evening sky. That night while Mother and Father washed the supper dishes and put the young girls to bed, Mateo asked if he could accompany his grandparents to view the comet. Mother knew that her parents would be watchful of her son and sent him on his way. Father recalls, "*Mateo came and asked us, as we were doing the dishes, 'Grandpa and Uncle and Grandma are going to look to see if they can see [the comet]'. So, they were going to go out for a little drive to see if they could see this. It was getting late, but we said, he always loved to look at the stars, 'We're on vacation, so sure, Mateo, go ahead'. So, he quickly put his sandals on and left.*"

They had no concerns for his safety as they knew his grandparents were very protective of their grandchildren and would alert them to any danger, Mother tells of Grandma's watchful words to Mateo, "*Mateo, in the meantime, asked Grandma, 'Can I go with them?' [Grandfather and Uncle had already crossed the road for a better view.] And she said, 'Oh, sure you can, but be CAREFUL when you cross the road'.*" It appears that Mateo lost his sandal while crossing the busy roadway and went back to retrieve it, right into the path of the oncoming car. The parents recall, "*We feel, just because one sandal was laying way, far away from the body; the body was way farther down the road, and his sandal was here. So we feel what happened when he went out of the house, I mean he was in a hurry, he didn't do up his sandals properly. He ran across the road. He lost one sandal, so came back. . . .Because he knew how to cross streets. He did it all the time. . . .But then he probably saw he lost his sandal. And even though he saw the car coming, he thought, you know how 8 year-old boys [are], 'Boy, I'd better get my sandal off that road.' It's too young for kids to be crossing the street because they can't; they can't judge. . . .And, as far as they [the police] could determine there was no way that that accident could have been avoided.*"

As her parents and brother approached the house on their return from comet watching, Mother could tell immediately that something terrible had happened. "*And then Grandpa came in, and we knew something was drastically wrong. . . .I had never seen him like that before, or after.*" Grandfather told the young couple that there had been a terrible accident and that Mateo was on his way to the emergency room. Grandmother, in tears, said that she would stay behind and take care of the girls while Mother and Father accompanied Grandfather to the hospital. Grandmother told her daughter, "*I'll pray for you every day.*" She was just sobbing. Poor lady!

Uncle, too, remained at home clearly devastated by what he had seen--his nephew flying through the air after being hit by the car. To this day it is too painful for Uncle to speak of Mateo's accident and death. Father adds, "*See that's one thing Uncle and Grandma and Grandpa basically did for us is be there, and we didn't have the horror. . . especially Uncle. He couldn't handle talking to you. . . .He was a 36 years old. . . .It hurt too much.*"

On the way to the hospital, Grandfather related a minimum of information on the accident and cautioned the couple that the outcome was not likely to be favorable. On arriving at the hospital the couple was ushered into a room where they saw the respirator attached to the small boy. Mother was surprised to see that his usual grayblue eyes now looked hazel. She realized that the sweet lively little boy that she knew had been taken from her and that only his body remained on this earth. After seeing Mateo, they met with the doctor who told them that indeed Mateo was brain dead. Father recalls, "*We saw him and we looked at Mateo. And they didn't really say too much. So I just looked him right in the eye and said, 'Tell us, Is he gone? Is there any hope?' He said, 'No. We tried our best and there's just no; he's had too much head trauma that his brain is dead. There's no – he's not'.*"

Shock descended on the young couple. Father stood at the bedside as a ferocious anger began to fill him. He says, "*At that point, I had such anger. Oh! I just remember being so angry just thinking about, 'Why didn't they take more care of him? Why didn't they, why did they even let him cross the road there?' I don't know if I even knew the details at the time. . . .Now I just look back and I see this as God's grace again, because in that moment when I had that, just that terrible anger at the family, all of a sudden it was just like (snap) a thought came to my mind. 'This is not right. We are going to have to accept this, as this is just Mateo's time to go. This was his life. We're going to have to accept.' And I remember very clearly, Mother sat down in a wheelchair out in the hallway. She had gone out in the hallway and sat in the wheelchair and was sobbing there. And I remember bending over her and saying, 'Mother I want to make a commitment to you right now, that I, we are NOT going to put this blame on the family because . . .we're just going to accept and just believe that God is in control and that it was Mateo's time to go. We had no control over that'*".

In that moment, he knew that should he remain angry with his in-laws, his marriage and family would come to an end. He turned to his God and prayed for the anger to be taken from him. Immediately, it was. Mother could not understand at that time what Father meant. Why would she blame her parents? Her mother was, if anything, overly cautious when it came to supervising the children. She adds, "*My mother would always be the one that's always [reminding us] to be careful. . . .So, when she let him cross the street, I knew she had been careful. So, to me, it wasn't a big deal.*"

She felt surely this was simply an unfortunate accident that could not have it avoided. God had called home her little boy-- why, however, she could not fathom. At the time, Mother did not understand the loving act of forgiveness that Father was performing. Mother and Father had a decision to make: when was the respirator to be turned off? Mother remembered a friend who worked in the operating theaters at a local hospital back home. This friend had once told her of her job to assist the many surgeons who were harvesting organs and tissues from the body of a young man who had been killed in an accident. In this moment of loss, she too decided that the loving act of organ/tissue donation should be accomplished so that Mateo's death would be of benefit to another family. Unfortunately, due to the damage done to his body in the accident he could not serve as an organ donor but heart valves and corneas were donated. There were so many papers to fill out at the hospital! Aunt P., Mother's eldest sister was a nurse, and acted for the family to complete paperwork and make arrangements for transfer of Mateo's body to the funeral home. She remained at Mother and Father's side long into the night to accomplish these tasks. The next day, she continued her duties in assisting Mother and Father (together with Grandfather) at the funeral home making arrangements for Mateo's burial. Mother recalls her loving care, "*And if I couldn't handle something, someone else took over. Father and Aunt P. did the whole eulogy. I was standing there and Aunt was typing while Father was talking and I was talking. And I said, 'I can't handle it.' And they said, 'Okay. Go. It's okay.'*"

Back at the house, many visitors came to call and give their condolences. Some stayed just for a moment bringing food for the family while others remained, asking many questions, themselves in shock that such a spirited little boy could be taken from life so quickly. Grandmother and aunties performed the duties of accepting condolences, and encouraged Mother and Father to take their daughters to the park across the street whenever Sister 1 showed signs of distress at all the commotion. Mother recalls, *I think sometimes I worried about Sister 1 because I didn't see her crying. And then she would say she was crying in her bed. . . .but her gauge of how much she was hurting, was her tummy aches and her headaches. . . .And as soon as, that's the only way I knew how to get her away as soon as possible. . . .But she was in a little cocoon there, too, nesting with her aunties and her uncles.*

While both girls were really too little to completely understand the death of their brother, Sister 1 understood that something serious was happening and that her brother would not be coming home. She says, "*Well I remember; I don't know why I remember this, but the day that I found out he died, I remember waking up, because we were sleeping on the floor. And there was a pillow; he was sleeping right next to me, and there was a pillow where he was. And I remember thinking, 'Oh, he must already be up'. . . . But I got up and then my parents told me Mateo had died last night. I don't even know how I really felt. . . .I forget. But I remember the strangest things.*"

Sister 2 simply remembers going to the park and with a young cousin pulling bark off the trees-- one must guess that this memory is more a retelling of the event. She says, "*Well, I remember doing it. . . .But then I saw the video and that sort of brought back more memories of it. I also remember things like stuff that I did in the other house, where Mateo was alive. . . . Except, I don't remember doing anything with him in that house. . . .And I picture it as in our house. . . .Like, doing stuff that I did, there, in our house. . . . So, I don't really know what I did when Mateo was alive. . . .It's sort of hard to figure out."*

The family arranged for the funeral to be held in the tiny town where Grandmother and Grandfather lived, since so much of Mother's family was present. Father phoned his mother with the tragic news of Mateo's death and she, accompanied by a number of Father's siblings, flew down from Canada to attend the service. Father made one more phone call to a church family member in their hometown and the word quickly spread that Mateo had died. Mother wanted the community to know quickly so that children in Mateo's class could be given help with their grief—a thoughtful and loving act from a bereaved mother. Since Mother and Father were without 'blood' family in their hometown, they had bonded with four families from their church and one neighbor who they considered 'like family'. All of these people made the long journey to the southern United States to support the family at this difficult time. Mother and Father felt honored by this support. They report, Father: *"I was delighted to see them come. There was a familiarity down there in (name of town where Mateo died) because, of course, down there we just knew the family there. I mean we knew people there but not in a closeness, like these couples that came down. So, to have some, I think that's probably the main thing, is that people that are close to you, when they come, it means more. . . .Well, the familiar, when you're going through something so unfamiliar; that was completely unfamiliar territory for us. . . .And to have people come down and there'd be some stability there and some people there that were there. . .just to support us through our time of grief and burial, that whole thing that was"*. Mother: *"When two of your close friends come to the Funeral; and all the other people come, it gives worth to us and it gives worth to Mateo. . .and, I think that's so important, even though they might not be there in the years to come. . . .They show that . . .you're important. . . .And that your grieving isn't—but it gives you worth, that what's happening is important. . . .So, when people like that come, they honor you. They honor your son"*.

Many members of the grandparent's community also supplied support to the mourning family, including help preparing the funeral service, supplying musical accompaniment, and preparing a dinner for all those attending the service. Many years before, Mother had a friend whose husband died out of the country and she remembered the difficult chore it was to bring his body home. Since her Father was a minister often assigned to out of country churches, the family did not visit the graves of deceased relatives. Mother felt that Mateo would be remembered, no matter where he was buried. The couple decided to bury Mateo where he had died, and bought a plot next to other family members' plots.

As the family waited for the day of the funeral, they gathered and watched videos, recently taken, of Mateo having a grand time on his holiday. Ten years later, at the time of the family interview, it was not difficult for Mother and Father to remember the details of that week which seemed to stretch on and on. In arranging for the placement of a special memorial stone on his grave, the couple decided that the spirit of Mateo should be evident and that his short life should be remembered. Mateo was a spiritual boy who would speak of heaven and insisted that when Jesus returned, he would be walking down the street and he would say to Jesus, "*Hello, Jesus! I'm Mateo*!" They recorded his full date of birth and death on the tombstone—they wanted every precious day of his life honored. They then boarded the plane for their trip home and their next duty, to hold a memorial service for their friends and family in Canada. Mother realizes, "*The first bit you're shocked. You can't believe it; but you still function. There's all the stuff to do; but I had plenty of people to help me. It's really unreal. And there's different things that. . .you end up saying goodbye to parts of it. Like, getting back to the plane and realizing he's in [the U.S.A.]. And he's not coming back with you. We all got on the plane, and if the plane went down, we would have been just, 'Oh, well. Just so we all go as a family.'*" It took a total of three weeks until all these events were all accomplished, Mother recalls, "*So we came back home and then we had to do a Memorial Service here. . . which always puts you in limbo*". They also had a tree planted at Mateo's local school in memory of him.

Then the work of restructuring their family began. Father recalls, "*Well, in that first while, I was never one to shed tears, but I couldn't; there was a flood. I remember the first days, especially when we got back here and everything. Of course, at the Funeral, you stay so busy, getting everything all prepared and so your mind's not. But as* *soon as you get back into the routine of things, then all of a sudden, it hits home. I spent many a night just . . .mourning".*

Suddenly they were and "all girl" family, just at a time when Father was enjoying the activities of father and son--playing ball, going to soccer games, working together in Father's woodworking workshop. While Mother felt "*I have lost a child, Father had lost a son,*" recognizing that her husband had an even greater loss to grieve than she had. Father adds, "*A new family doesn't just start like that (snap). You have to, it takes time. . . . It's just there".*

Mateo's room, just recently changed from Sister 2's nursery, was slowly emptied of his clothes and toys. Each morning on awakening, Father would "*Glance across to the doorway that's Mateo's room and all of a sudden [the sound of snapping fingers] it hits [him] again. Oh, he's not there!"* Some of his things were passed on to his sisters and cousins, while others were simply given away. Some special mementos-- his soccer trophies, "shark gloves" and other precious items-- were placed in a waterproof box for safekeeping. From time to time over the years (more at the beginning of their bereavement) the family would bring out the box and remember Mateo as they looked at his things.

Mother, a stay-at-home mom, had little energy but realized that she needed to continue to care for her young girls. But she adds, "*I quit the stuff I was doing at Church that was involving his age group. I quit that until the end of the school year. . . .And I was busier doing stuff at Church; and they knew I just couldn't do as much. . . .And people understood it. . . .You're so preoccupied with your pain. . . .That you can't do as much".* She tried to keep busy cleaning house, playing with the girls, and making meals—friends had filled her freezer with meals, a support they thoroughly appreciated. Mother adds, "*Because you're a mom, you're dealing with the other girls. So that helps because you stay busy. But you still are not running on all cylinders. You're definitely not functioning. And, because of that, you're very grateful for all the food that people give you, that's in the freezer. [And] I couldn't handle some situations; it was just best that I didn't go, just because you're reminded of what you've lost, by going by soccer fields [or other places]. That was the first year. I don't have a problem with soccer now. But years later, when his group of kids left 6th grade left the school, and again, when they graduated this year, that was a bit of a blurb of a grieving".*

Father found that, while he returned to his work as a self-employed renovator almost immediately, he did not have the energy to do a full day's work. He says, "*I would* *say that that in the initial stage of grief, you're so overwhelmed and preoccupied with what's happened. . . .That everything else; you're only running, I don't know, 50%. . . .You know, functioning in the other areas of responsibility that you have"*. He also decided that it was important for him to be at home more, and so he lingered longer at lunchtime and put in shorter hours. His customers were very understanding, urging him to take all the time he needed to complete projects in their homes. He adds how these kindness acts were valuable to him, but also served another goal, "*And the other thing is, in that whole thing, I see it, too, and we graciously accept all these gifts of kindness or love, recognizing that the people that are around us, that know us, and knew our family, they also needed a way to express their own grief, and by doing these sort of things, they were contributing or helping themselves. . . .Like, it's a healing thing to be able to go and, give support to someone"*. Slowly over the first year of bereavement he was able to return a full day's work but never again to the long hours on which Mateo had commented just before his death. The couple, Mother said, felt, blessed that [we] had other. . .children because . . .it keeps you going.

Father remembered, "*At the start there, oh, it was so good to be able to . . .just take them in your arms. . . . my younger daughters, who they are, and of course, when you go through something like that, lives around you are so -- you recognize them so much more, as how important they are. . . .And so then you . . .the girls were sort of a way for me to, I couldn't hold Mateo, but with them it was sort of a way of a comforting thing. . . . And of course, they're all smiles"*.

While they had been in the process of moving to a bigger home before Mateo died, they chose to postpone this move to give them time since they felt "*that first year you're in gaga land most of the time.*" When they moved to their new home a year later, they did not set up a room from Mateo, but only kept a collage of pictures [made for them by a sister] of him up in their hallway, where it remains and always will. When the calendar year came to a close that first New Year's Eve, mother was "blindsided" unexpectedly by the ferocious return of her grief. "*When everybody was giving each other hugs, at the, when 12 o'clock hit, all of a sudden I realized that I was leaving the year that I had Mateo. There would be no more Mateo in the next year. . . .I can't pull him into the next year. That year is where he stops"*.

The family now is a new family, realizing how poorly one functions during the first year of bereavement. *"The days somehow pass, even when the deep pain convinces you it will never go away. . . .I think you get used to not having him around. . .*

.And, like we'd go to Church, and you'd expect someone to be about that high [holds hand up at the level that would be Mateo's height] sitting next to, standing next to you. . . .And the next one's down farther". But the pain did get better and the "*memories fade*" and somehow the family got from one day to the next. Mother states, "*I think what you do is, it comes in waves. And in the first weeks, it's just a complete, you're dull. I mean it's just completely always in the; I relate it to being in the ocean. . . .It's always rocky. And then, after a while, it comes in waves. And sometimes you don't realize when it's going to happen. . . .It just diminishes".* But they have not forgotten the details of the death and at times the pain can return. For Mother high school graduation day brings tears. She says, "*I think you've gone through enough stages. I think you always get some, like when he, like with the High School situation".*

Father thinks of Mateo when he sees his cousins and their sons who are of Mateo's age out together. The couple wonders what life would be now if Mateo was alive—"*Would they count on him to pick up Sister 1 from her job? Would he be interested in working with Father in the woodworking shop? Would he still be playing soccer?*" Mother has learned to live with her loss but describes the bond that will always be between her and Mateo, "*Well, as they say, when you lose a parent, you lose your past. When you lose a child, you lose your future. . . .And, you always wonder how he's gonna be. . . . He's part of you. I mean, shoot, he's the one that taught me how to be a Mom because he was my first. . . .And the whole 9 months of carrying him and the whole thing, I mean they become part of you. . . .It's always there. . .because their beginning was with you".*

Other family members, too, have been affected over the years. Sister 1 had immediately following Mateo's death taken on a new role-- protector of her little sister. Father says, "*The other thing that was hard just to think about is: he was the older brother and he was such a, he was already becoming a protective type of. . .brother to the girls, and we just saw that as such a neat thing, too. . .But that was taken away, so we had to deal with that. . . .And so, all of a sudden, as I say, Sister #1 took the role of leadership. I mean we really saw that happen even at the Funeral, she already was protective of her little sister. . . .And we didn't see that before as a middle, middle child".* And sister 1 recalls, "*I remember I did different things because I was the older sister. Instead of doing things with Mateo, I started hanging out with my sister a lot more, and also taking more control of doing things. . . .But, not that much changed".*

Sister 2 struggled to remember Mateo. Some 8 years later she became very interested in family stories, photos and videos as she struggled to understand who her brother was and what his life and death meant to her and to her family. She poignantly recalls her struggle, "*I got to the age where I was aware of what happened to Mateo. . . . And the fact that he was gone, so that was sort of like where [I] thought . . .they had it. They were done with it, a couple of years ago. And then I started, sort of grieving. . . . Well, I was at the age where I realized . . .it was sort of like I wanted him back. That's all. . . .One night I was just thinking about him and just like . . . wanting to have him back, just a need for something. . . .Lots of people say a part of me was missing. . . .But I don't know if it was that or something else. . . .It was just, I needed something. . . .I talked about it with my parents. . .and then, sort of, it stopped and I just realized he's not coming back. And. . .what helped me was I knew that he was in Heaven and he was in a much better place than us. So, that helped*". Sister 2 adds how she senses the strong connection between them. She also realizes that Mateo's presence in their family has been critical to whom they are today. She adds, "*There are these people at Church who have a brother 2 or 1 year younger than Mateo would have been right now, and I don't know, it's like seeing what I would have been like . . .what my family would have been like. [And] we would [be different]*".

Extended family members, as well, played important roles in the Schmidt family mourning. Grandfather, a stoic man, performed a loving act by keeping true to a role he believed was needed---to remain strong and support his family. It took him one year to allow himself to cry in the loss of Mateo, for he believed that to do so earlier would add to Grandmother's unbearable pain. Mother recalls, "*A whole year later! And he said he didn't want to cry because he didn't want to add to Grandma's pain*".

Mother thinks about her mother's pain and realizes how devastating this must be for a grandmother, "*It was; it was really; I mean she's a Mom. She's used to being in control and making things better. . . .And for a Grandma to handle that. [struggles for control]. . . . It was; you can't get any worse than that. . . .And my friend, who used to call me every day after Mateo died, she said, 'You know, she did the best thing a mother could do for you, is take that whole trauma away from you. That I didn't have to be there when Mateo died'*".

Mother now realizes what a loving act Grandfather and Grandmother performed at the scene of the accident. Her memories of Mateo have always been ones of "*the sweet little boy*" who was having so much fun on that holiday. She was spared the horror that Uncle witnessed of a small child flying through the air and landing on the pavement, the terror of the grandparents when the ambulance attendants attended to the injured boy and instructed them to send the parents to the hospital, warning them that there was little hope for survival. Grandma was asked to take part in the family interview but, while she was unsure what she wanted to do, Grandfather decided for her to revisit that pain could jeopardize her unsteady health, and the couple chose to decline to be interviewed. At the time, Uncle, too, kept to the stereotypical male role and did not cry. Mother says, "*Grandpa, Grandpa and Uncle, you would say they were like the typical male.*" He, too, did not want to re-experience the pain while being interviewed. But Father demonstrates an opposite male reaction: *"(He) cried lots. . .and (mother) could talk to him about it. And he could talk to (her). . .and (as) one of (them) might be having a better day than the other . . .(they) would still share".* Mother remembers the look in her mother's eyes, pain so deep. This pain shared over the years but "*healed*" now by belief and trust in her God. Mother explains, "*[God is a father who] knows me and He loves me better than my father. Because I could trust my dad, I could trust my heavenly Father. So I knew there was a reason for [Mateo's death]".*

Mother and Father have come to view their bereavement as "*almost a special time.*" Father further explains, "*Well, it's the fact that, and I don't even know how to express it clearly. And it probably has to do with my faith. But the fact is, I believe that we never are put in situations, allowed situations that God will not also give us the ability to cope with. And that's, I believe, that's why He allowed us to go to that marriage seminar before. . . . He was preparing us for this. But, in that sense, I almost, there's, sometimes there's a sense of, 'Why me? Like, why, why did You choose me to go through something like this and think that I was worthy, almost, to go through a time like this?'. . ..It's that thought, like it's almost, it becomes almost like a privilege. . . .That we were, that I was allowed to go through a time like this; that I was chosen to go through a time like this. . . .Because He saw me as someone that He would be able to give what it takes to cope with it".*

The family has learned to be more accepting of the pain of others and, while talking to people, use their experience and growth as individuals to "*minister to others*" knowing "*you have to go through it. . .you have to deal with it.*" Father adds, "*As time went on; that was fewer – my mourning, dwindled. . . .I mean it got; my mourning time was over. And life went on and, it was more the joy of memory and, talking about his memory with people around. When visitors come over or when I'm at the coffee shop,* *then it just, somehow the conversation leads to that. I don't go and tell people, 'You know I lost a son,' or whatever. . . .But no, if the conversation goes that way, I can say, 'You know, I can relate. Do you mind me telling you a little bit about the loss I had?' Well, of course, he was forefront in our minds for the first, so that would be the conversation and that would just come up because people recognized what we were going through. And so we always said, 'Listen, we don't want you to feel uncomfortable around us. Let's talk about him.' And people needed to talk about him, so. . . .Even others that were, that knew him, or us, they needed to talk of him. They needed to know where we were at."*

Their openness in talking about Mateo to each other created a closeness. Father says, "*And if you go to your own room, and do your own mourning separately, one from the other, that's gonna . . .I believe that's going to pull you apart. . . .And there's a bond there. There's a deeper bond, I think, in our family because we all feel that we know what we've come through. And we've come through it together*". Mother adds, "*I think it really helped that Father communicated, was a communicator. . . .So we worked; from the very beginning, I think, we just, we talked it out. We were able to talk it out. . . .I didn't have to go to my friends to talk it out because my husband and I talked it out. . . .And he was willing to cut back in his hours so he wasn't so busy. . . .If I was having a bad day, if I missed him for some reason, I'd talk to Father and vice versa. . . .And because neither one of us went on the deep end. . . .We didn't feel like we had to. . .not share. . . .I didn't feel I had to protect him from his grief. . . .And I think we just did it the way. . .I don't want to say instinctively, but we just did it the only way we knew how*".

When Mother speaks of her grief and mourning today, she explains the changes over time this way, "*I am no longer grieving or mourning Mateo. . . .I mean . . .I will, maybe, on a certain day. . .grieve for him and the loss. . . .But, we have gone by that a long time ago. . . .It doesn't control my every thought. To me, I think of him as my child, without the hurt. Number one, he has no needs. You're always thinking about your kids' needs. . . .So I don't have to worry about his needs. But I still think of him*".

She believes they made it through this tragedy because, "*We were working together. . . .There was a oneness. . . .And there was no, there was no blaming, because we weren't there. . . .It's amazing what people can blame themselves for. . . . But there was definitely an oneness in our, in our grieving*".

"It's forever a part of you, a journey that you carry; it's true love"

A Restructured Family, Putting it all Together:

The Story of the Broders Family

The story of the Broders is told by Mother alone. The many years Mother led a group for bereaved parents and her interview served as verification for my emerging theory of family bereavement. She was in agreement that bereavement is work. She also related that in her family, she worked with her husband and two surviving daughters to create a new family where Katrina is remembered and has an active place. In the interview as she related the story of her family I was able to understand the co-construction of the emerging family following the death of Katrina. She relates how her husband endured, taking care of their surviving daughters in the moments when she herself needed to be absorbed in her mourning. She further spoke of the work that her young daughter did to assist her in the suffering-- bringing her comfort through her hugs and reminding her that she was needed as a mother. In the early years of bereavement, Sister 2 often triggered the awareness for Mother that she needed to return to an enduring mode so that the tasks she cherished as a mother could be continued for her surviving children. The couple created space for understanding for each other's individual needs in grief and mourning. Further, Mother learned to value her suffering and give back what she's learned during her reformulation to members of the bereavement group she led.

This family did not have the basis of cultural or religion that some families have to guide them through the rituals associated with the loss of a family member, but they constructed their own rituals of remembrance-- the pink roses and balloons of each family event. Even now after 14 years, they continue to mark a place for Katrina in important family celebrations. They actively told the stories of Katrina through the use of photos and family videos, and in many small reminders hidden away as sweatshirts in the closets or scraps of paper in the memory box. They enlisted the aid of extended family members through phone calls and visits at the holidays. After 10 years, Mother realized that Katrina had a firm place in their family other daughters, still going through adolescent developmental stages, needed to continue to create that place for their sister as they worked to separate from family. Today, they are new family, where Katrina's place is the true love of a child amid all the evolving routines and roles that families engage in over a lifetime.

Telling the Story: The Spirit of Katrina

When six year old Katrina suddenly and without warning displayed symptoms of an impending life-threatening condition Mother's instinct shifted into high gear to handle the crisis. Mother recalls, *"Our middle daughter yawned. And there has to be [something] said about maternal instinct, because I just had the feeling it wasn't a right yawn, if there's a right or wrong way to yawn. I felt so strongly that I just told her to get her jacket and we were going to run over to Emergency. . . .But before that happened, she was bouncing off the hallway walls and I had already called 911. Father had already picked her up and she was screaming: her foot was burning, her hand was burning and her head was burning. And he laid her down on the couch and she screamed that her head hurt, so he picked her back up. The paramedics arrived. . . .And we got to Emergency. . . . She was clearly showing the signs of having a seizure. . . .And I remember the Intensive Care Doctor who first attended her, looked at me in a very, almost scolding way, saying, "Do you have any idea how serious this is?" And, of course, I didn't. I was just basically running on instinct at that moment. [She adds], I believe there was controversy about operating on her. . .feeling that there wasn't any hope."* After the surgery, however, the surgeon *"was basically doing cartwheels"* because it went so well. But soon Mother could see *"it didn't look good."* Katrina died, leaving the space that is still visible 14 years later.

This year, Sister 1 was married to a young man who had also lost a brother. During the marriage ceremony the young couple decided that they would like to light a candle in honor of their siblings and ring a bell to call them to be present and witness the event. Mother was deeply moved by this very loving act and reminder of Katrina's place in their family. But, as she watched Sister 1 and Sister 2, she was aware, *"But it was interesting, because we'd been sitting there looking at her and her sister together and their arms were touching. And I could see the big hole where Katrina should have been . . . .It was just the depth of the pain that was hard for me."*

Over the years, the family has had many ways of remembering Katrina. These remembrances began when Mother insisted that, *"I'll do a eulogy."* And he [the minister] was like, *"Oh, you can't do a eulogy."* [I said] *"It's my daughter. Yeah, I'm doing a eulogy. That's my goodbye to my little girl."* It continued over the years with the establishment of traditions such as, *"We'd buy six pink roses, when anything was going on, we'd always have six pink roses. And amazingly, one would never fully open, it was like she was telling us. So we'd buy six roses and we'd all try and bet which one of the six wasn't* *going to go full. . .six because she was 6 years old. . . .But she didn't make it to her 6, to her full 6th year."*

In that way, the family began to create the spirit of Katrina that lives on today in the yearly celebration, now planned by her sisters. The family realized that they needed to do something that would fit with who they are now, a household of adults. Mother says, *"Now we decided that I don't need to do anything any more but the girls do, so they do. So I said, 'Let's decide something that will work with your own lives.' So what we've decided is, in November what we do is, from October to December, in that vicinity, if there's a good concert coming to town, we go as a family. The way it worked it out, we looked at it as it was her forcing us to quality family time because any time you asked her what she wanted to do it was, 'Let's do a family day.' So we did that as our cue, as our reminder. And, on her birthday, we decided we would; it was a family day."*

The Family

The story of the Broders is one of a family journey over 14 years in which the spirit of Katrina has led to a "*tighter and closer family*". When Katrina suddenly became ill, many family members arrived from out of town to support Mother, Father, and Katrina's two sisters. Mother remembers, *"I was amazed at the number of people around me who were . . .displaying such a sense of denial and such a sense of false hope. . . .And I remember one day, one of my sister-in-laws saying, 'I'll sit with her. Go out and get some air and maybe something to eat." And my youngest sister-in-law, who was my soul-mate, when we walked outdoors; she looked at me and she said to me, 'I'm sorry about my family.' And I said, 'Well, you know, they're holding on to what needs to work for them right now.' She said, 'Do you want to say something?' And I said, 'Yes. Katrina is going to die.' And it was like a weight had been lifted off my shoulder that I was allowed to say that."*

While she was present at Katrina's bedside, Father was *"playing the role of the ultimate host"* to the 30-40 family members who had flown into town. *"So obviously the level of denial was obviously a family trait. . . .And I looked across the bed; and he was just starting to break down and he said, 'I don't know how long I can do this for.' And I said, 'Do what?' And he said, 'Well, how am I going to put on a show for all these people?' I said, 'Do they think they're here to be entertained? They know what's going on.' . . .That was just the way he dealt with the shock."* Mother too resorted to her previous pattern of coping. She states, "*And,* [pause] *it was [a] really, really lonely time* *because* [struggles for control] *I was there with 50 friends and relatives and I was the only one that's digesting the truth. . . .I remember feeling the most alone in my whole life. And on one hand, the weakest I'd ever been, and on the other hand, knowing that I had to be the strongest I've ever been. . . .And I thought, 'Okay. Well, I'll have to put the heart aside and kick the brain in and get this done."*

As time wore on Mother recalls, *"The nurse in ICU who told me that, through coma, the hearing is sometimes the last to go. So she [told me to] say anything that I could; and I did. . . .In fact, I had the girls come in and say what they wanted to. And I told my husband's family to come in and say what they wanted. And I talked to her the whole week that she was here, like she was listening."* Over the years she has been comforted as she remembers this experience and states, *"I'll always be grateful to that nurse."* She has other reminders of those days spent at the hospital, *"I have her blanket and her stuffed animals. And when she came back from surgery, I said to her, 'I'm going to go; Dad's gone home to get Peanuts.' She had this little monkey she called Peanuts. And when he came back, he said, 'Honey, I brought Peanuts.' And she grabbed his tail and held on like you wouldn't believe. And the nurse said, 'She's in an induced coma. That's just a nerve reaction.' . . .Father said, 'No. It isn't. She grabbed Peanuts."* The family feels that Katrina knew they were there with her.

When she was declared brain dead, Mother recalls the neurosurgeon, *"was crying as hard as I was."* The family had decided to donate Katrina's organs for transplantation, however, a terrible event occurred that led to further pain for the family. Mother remembers, *"I ran into Dr. S and said, 'You know, we're an organ donor family." [But] the chain of events led me to believe that she could be there for a week, being harvested until they found. . . .And I thought, 'No. She can't; she can't do that any more. She's just a little 6 year old and no, we're just going to have to change our minds."* Unfortunately, another doctor was on duty at the time and when he heard that the family had changed its mind about donating Katrina's organs, he asked Mother, *"How are you going to live with yourself, knowing you didn't fulfill her final wish?" And I said to him, 'She'll be fine. She's 6 and really used to me making her decisions.' . . .That's when we met K. [the transplant program nurse], a young woman; and she explained everything over and over. . . .And that's how organ donation should be approached. . . .That night she went in for retrieval and then the next day we started planning the Funeral."*

In preparing the funeral, extended family members performed many kindness acts. Mother says, *"And Father's sisters were great. They went and organized all the* *food. And my brothers were amazing; they got all kinds of wine. And we ordered 75 pink balloons to be delivered to the house."* These acts not only spared Mother and Father work, but it also allowed family members an important way to give support, while also serving as a distraction for their own grief. Mother recalls that when she gave the eulogy for her daughter, *"I was in absolute shock and I was so blessed to be in that way. I was; I was handling everything. And (sniffs), so then I got up and did a eulogy. . . .And I was so glad I did it. And then we came back to the house, and everybody released a pink balloon."* Although family members were astonished by Mother's ability to deliver the eulogy, Mother was coping the only way she knew how in this time of crisis. *"That first little while, I could function in a veil of shock. I could really put my mind around a level of denial long enough to get me through what needed to be done. But when the veil lifted, the fear of the death, of that pain, it just scared everything out of me. And then it was compounded by, I looked around the night of the Funeral, and I looked at my brothers, and there they were, grown men, married with children of their own, looking at me with the most amazing fear. . . .My thought was, 'What's wrong with my brothers?' And they said to Father, 'All along she's held us all together. If she loses this one, what's going to happen to us?' . . .And I thought, 'Well, they have never seen me weak."*

She continued to cope with patterns she had learned previously - she needed to create space for her grief. Mother states, *"So, the day after the Funeral, I got on the plane and went to Victoria. And people who know me know that, when things are really difficult, I need to be alone."* She went to a secluded lodge, *"And it was the type of place where you didn't think. Your meals were prepared; tea-time was prepared. You had no reason to think."* But family members worried about her, "[My sister-in-law] went and spoke to my friend and said, *'We're scared she's going to do something to herself."* But thoughts of self harm were never in Mother's mind; she just needed time alone to collect her thoughts and sort through her feelings.

After a few days, Mother returned home where the reality of the family's changed life hit hard, *"And by that time, everyone had gone. So, you're walking in to what used to be. And it was very difficult to create our new normal; and it was very amazing how . . . people just want to avoid you. . . .Which, you're already feeling so strange in your own environment, when people are avoiding you; you're feeling like a very strange being. (laughs) The only thing that saved me was, little kids. . . .[They asked] just the strangest questions. One said, 'Well, if the Doctor found it, why didn't they fix it?' And that was my question forever."* But the family soon learned that life was not going to return to the way it had been; there was no normal. Mother soon learned that each family member had their own unique way of enduring and suffering the pain of Katrina's loss. *"We weren't together. [Father] went to work and I was a mess. And he came home and kept the family together. . . .And his grief time was driving. He talked to Katrina. He talked to God. He'd freak out. He wasn't a pleasant person to work with. . . .Short-tempered. Curt. Abrasive."* Of herself she says, *"I'd always get out of bed. I always had a jump-start on the morning. And then he would find me in a corner of a closet, huddled, screaming like an animal. I was scared the neighbors would hear me scream. So I had pillows with me. I'd be screaming because I just, really I couldn't understand how you could hurt that deep."*

Sister 1, who was 8 years old, was having difficulty as well understanding the death of her sister and what it now meant for them to be a family. Mother recalls that she *"was a wreck by Christmas, so I pulled her out of school and I did Home Schooling. . . .So what was happening was we were trying to be at home here and say, 'Something has changed, but there's still a lot [of things]that are the same. . . .We're still the same family. We're still strong and tight. Katrina's always going to be part of our life.' And then she'd go to school and they'd say, 'No, you don't count Katrina any more. She's dead.' So, she was getting two messages. . . .And she was asking, religious questions. And I had a great Minister at the time and I'd phone him up and say, 'Your department, you get over here."*

But it was Sister 2 who helped Mother to come to grips with the reality of the family's new life. *"But, little people, Sister 2, she completely took it in perspective, on an ongoing basis. I'd pick her up from school and I'd be crying because I missed Katrina and she'd say, 'Mom. She's gone. We've got to move along here.' [said with emphasis][(laughs] And she'd be like 5 years old."* Sister 2 also took on the role of comforter to Mother. *"I have a picture of Katrina and I was crying really hard one night. And she just always went down the hall and got Katrina's picture and gave it to me. And, one night she gave it to me and I said, 'I don't want this picture. I just want her to hug me.' And she said, 'Well, I'm here. Hug me.' [laughter] And I got all my parenting classes with my youngest daughter. [laughter] And I thought, 'Yeah. No kidding. How does this kid feel? All I want to do is cry.' So, every time I cried, she hugged me, instead of bringing the picture. . . . After that, she never had to bring me the picture again."* These loving acts, performed by one so young helped Mother to emerge from her suffering and begin to reconnect with her strength.

Another event with Sister 2 demonstrates how children can assist adults to accept death. *"Sister 1 was extremely self-sufficient. Her and Father would have been very fine together. But then I have this baby constantly at me to do stuff."* Mother adds that a couple years later, *"One day I took her to school; and she was older than Katrina. I thought, 'Well, how does that work?' . . .I've always been a numbers freak. . . .I'm just terrible; how can her little sister be older than her now? And she came out of school and she said, 'Mom, give the numbers a break.' She said, 'She's gone, so put all that energy into me.' And I remember I always said, "Sister 2, you saved my life. You saved my life.' . . .I didn't want to function any more. . . .She totally did [save my life], with her honesty, her frankness and her total lack of fear of saying something direct."*

While Mother was able to return to performing many of the household tasks she found that, *"I was walking beside myself watching myself. That's how I functioned for 6 months . . .I was in the third person. I was, 'Oh, look at you. You made that cake.' . . . You know, while I was making that cake, there was this thing behind me, trying to prop me up. It was me; it really wasn't me. It was my mother. . .something was pushing me on."* But she felt unable to show her pain or share it with others, *"It was something I didn't feel always right sharing because I felt there was a lot of judgment. And even in my own family, I felt like I was one of the damned. . . .And it weighed on me forever."* While there have been many acts of kindness given to the Broders, Mother recalls that there have been family members who were not. She recalls, *"I had an aunt that used to be really close to me . . . .She kicked me when I was down like nobody's business. Her attitude was: you just have to move on . . .like, just a month later. . . .All the people who gave me this, their great advice, I thought, 'I don't quite remember when you had a kid die?' I wasn't quite sure where they were getting all this profound knowledge of what I was supposed to do. . . .[But] I was smart enough to recognize that I wasn't going to connect with that person through this journey. . . .So, maybe the first, second, third time out, I thought, 'It's not going to fly; I'll let it be, so I just sort of put them aside. And I didn't need anything because there's nothing anyone can do, but just let me cry."* Other relatives who had a difficult time just listening to Mother's pain, offered practical help, but *"I didn't need anything. . . .You know, I do have some wealthy relatives who want to send me on trips. 'But the tears are coming with me. Thanks, but.' But they would just, they could say to me, 'I know what you need, and I need to do something for you'. . . . No, you don't fix this with a trip."*

Mother was enduring perhaps because of prior beliefs that she held, including a definition of herself as a strong person and her duty to others. *"And they [other family members] were just scared; no one had ever seen me like that. I'm the one that takes charge. . . .And now I was going to let them down, so I was going to be a wreck and then I was going to make the rest of them a wreck. That's really very selfish. So, you don't do that. . . .I always felt it was our business to deal with it."* She suffered in her loneliness and fear, *"I always felt that the last breakdown might be the last of everything....But this was such a heavy hit. . . .You just start feeling like there's something wrong with you. You're a bad person. Maybe God had it in for you."*

Mother was not new to the experience of grief; her mother had died when she was 16. At that time she was called on to run the household and raise her two younger brothers. But within a few years, her father married a woman whom Mother could not accept, *"It was very difficult to have her take over my mother's home. And, [it was like] we'd seen our mother evicted from her house."* She moved out on her own and in a short time her brothers also left home and moved in with her, leaving her the total responsibility of raising two teenage boys.

When Mother, in her grief, began to question her faith and called on her minister for help. She was asking, *"I've always believed there's a Higher Power. I was brought up in the Anglican Church, with Sunday school. And I didn't understand why God hadn't taken my name out of the hat. I didn't understand if I wasn't learning my lessons; that I had to keep getting them harder and harder. I thought I passed the test. . .so I thought I had done my time. . . .I thought I had proven myself. . . .In the years following my mom's death [laughs], I questioned but did everything. I thought I had succeeded with that learning. . . .I thought I got that lesson, you know."* But the minister convinced her to attend church and there, on special Wednesday services, she was able for the first time to sense the spirit of Katrina. *"So, the Minister tried to convince me [to go to church] . . . . And I tried it and it worked. And every, it was really bizarre because every Wednesday when I went, there was a little Katrina song. There was either a psalm she had sung or a Bible story she'd ask me to repeat, but it was things, some clue, that came."*

Mother and Father shared a similar response to God, *"But it was a time where I questioned . . .my faith. It was the first and easiest place to blame, to lay blame . . . . . Because we had nothing to blame; that's what Father's struggle was. He had nothing to blame. He couldn't say, 'We let her out on her bike without her helmet. She hit her head, or a car hit her.' There was nowhere to lay blame."* But later Mother realized that, *"Blame* *is a real easy out. . . . never blamed God for not being there. I never took that. I just looked at it as having this fear. Fear was showing emotions at that level."* She adds, *"I'm a Journal freak. I have a Journal that I started the day I was pregnant. I have a Journal I started with each girl. I have a Journal of conversations with God. And that's the one I want to be buried with, so He can read it. [laughter] Not that he doesn't know. But I just, I chose Him [God] as my place to blame this, as my sounding board."* But for some months Mother continued to hide her pain and sought ways to understand the pain she was experiencing.

Meanwhile, Sister 1 was also experiencing a crisis of faith; she was not willing to attend church services. Mother reports, *"Sister 1, on the other hand, would have nothing to do with God, on any level. Her attitude was: 'Why would you ask me to go to someone's house who killed my sister?' Mother adds that many years later, "When she was 18, she decided that she needed some religious belief and she went to Church a few times on her own. I think now she understands the benefit of it. She knows there's something there. You have to believe in something other than yourself."* While Mother had hoped that Sister 1 could find some comfort sooner in a belief in a higher power, the family created the space that Sister 1 needed for own work during bereavement. Mother did have some friends to turn to. Even in the middle of the night, when her grief seemed unbearable, she knew she could reach out to them, *"You know I have friends that I can just dial in the middle of the night and cry . . .and I would cry and cry and cry. And they just said, 'That's okay; call any time."* One of Mother's brothers would often come into town to see how the family was doing and to attempt to understand the reality that his niece had died. Mother recalls, *"He kept coming up here all the time. And then I thought, 'He doesn't believe this.' So once when he came up, I said, 'Stop coming up here all the time. She's not here. She really did die."* Later, Mother again needed to provide him with direction when she, following the birth of his daughter, needed to remind him that life does go on and it was okay to be joyful. She remembers, *"And when his daughter was born in November, a week after Katrina's birthday, he phoned to tell me. And it's like he phoned to tell me he got the tire changed on the truck. . . .And I'd say, "Where's the joy? Oh, my God, you got a daughter! That's so great!' I said, 'Isn't that wild, to see the baby born?' But he didn't react much. And I just went, 'Oh, my God, you can't pass this joy because of what we're experiencing.' I lost it on him. I said, 'Don't you dare; she had nothing to do with this. Let's have a party and embrace this little baby."*

Mother learned that some people could not bear to talk about the pain. One night in her pain, Mother intended to make a phone call to a brother-- but realized only too late she had dialed the wrong one! She recalls, *"And one night, we had speed dial on the phone and I wasn't doing well and I just didn't want to speak to Father. I thought, 'Oh, I gotta speak to someone.' I felt like I was losing it. But I crept out into the kitchen and I pushed Speed Dial and the phone picked up and I said, 'Okay. I've done this for so long, but I can't do it any more. I'm actually freaking out. I think I'm going over the edge. You've just gotta listen to me talk for a few minutes.' And the band was on and I started to cry and then I said, 'Oh, okay. Okay. I think I'm okay.' And my brother goes, "Oh, wow, you know I can't deal with this.' And I went, 'C.?' I said, 'Oh, God, I pushed the wrong button!' I said, 'I know you can't deal with this. I meant to call [other brother].' [laughs] And he goes, 'Well, I'd like to try.' . . .I just know how he was when our Mom died. And I know this was just too much for him."*

As Christmas came, it was not the usual joyful celebration and Mother learned to lean on the kindness acts of others to get her through. *"The first Christmas wasn't very good. My friends from Victoria came in, basically, just to sit and cry, but we did pull off Christmas. . . .It's like everything else; it returns to normal. Well, our normal didn't have any sort of continuity or consistency; it was very just hit and miss. [I wasn't] on top of things, which is not how we lived. It's not how I raised my family."* Mother realized that she needed to do something to cope with her suffering, *"I always did what had to be done. Just get er done. And I was going down fast and I knew it. And I didn't share it with anyone. I made sure I made a conscious effort not to let anyone know I was going down, but I was going down."* While she endured in this way, Mother knew that she needed to find a different method to deal with her pain.

After Christmas, Mother began to seek answers to her grief. *"And then I just sort of added one thing the next day and the next day. And then, after Christmas, I had read, 'The Bereaved Parent' [and it] made so much sense. I thought, 'These are things you're supposed to feel.' And that amazed me that somebody knew about this. . . .That was my biggest thrill. 'Oh, my goodness. Somebody knows about this.' . . .It never dawned on me for a minute; I'd watched my grandmother in such pain after my mom died. It never dawned on me that I had already seen somebody [grieve for a child]."*

However, Mother soon learned that society, in general, did not know how to respond to a mother who had lost a child, *"I'd go to Bereavement groups and it was all about loss of spouse, loss of income, loss of sexuality, loss of this, loss of that. And I'm* *mentally drained because this does not apply, this does not apply, [and] this does not apply. And I'm thinking, 'It's good to know I'm completely on my own.'" No one's feeling this; no one's experiencing this. This must be the onset of madness."*

While she recognizes today that awareness of grief and mourning *"has improved so much"* at that time it was the serendipitous presence of another bereaved father at one group that became a turning point in Mother's grief. *"I had gone to this Bereavement group where nothing applied. And I thought, 'I'm done. I'm done. I don't know what's going to happen to me now. I'm done. I can't pretend any more. I can't do this on my own. I'm totally alone. I'm the only one in the world that's had a child die.' [sniffs] And then a man stood up and said, "You know, respectfully to all you've said here, however, it's nothing like losing a child.' Then I lost it. I lost it. And it's obvious to everyone there, that's why I was there."* This bereaved father told Mother of a group just for bereaved parents. And she and Father, *"went to out first meeting, and I was just mesmerized because I thought, 'I don't know how these people know this stuff that I've been writing about in my diary.' I thought it was a setup. I was at the point that I thought Father had set it up. . . .And it's just such a bond. And I think, 'I'm bonding with all these absolute strangers. And they all get it. . . .And I left that night and, honest to God, I was. . .I was on my feet. It was a turning point because of the simple fact that I knew I wasn't alone. . . . I never, ever [again] felt doom and gloom and I'm done and this is only me. Just taking away that idea that there was no one else in the world who was living this. . . .I just did a 180 right then, the minute we walked out of that hospital [the meeting place of the group]. I thought, 'Hey, I can do this. Other people are doing it. I can do this.' And ,just literally, knowing that I wasn't alone. I don't even remember who was at those first meetings. But all I remember is, 'Other people are doing this. This is not exclusive to you."*

Mother began to believe that there was hope for her family; that they would create a new family of four. *"It's to realize that. . .creating a new normal, was going to be my job . . . . [Where before] He [Father] was making sure everybody was tended to. Basic needs. . . . But I've always been a very active, creative, nurturing mother. . . .And now, I didn't want to be a mother. Motherhood just hurt too much. And so I just backed off. He made sure everything was done. And I just kinda looked at my girls and thought, 'Katrina died. The rest of us didn't.' . . .As I came out of the ashes, he [Father)] felt more comfortable to lose it."* The family had created space for each member to do their own work of grief and mourning and was now prepared to do their work as family to make meaning in the life and death of Katrina, and to re-member themselves by creating her spirit that would have a presence in their ongoing family life.

Armed with this new awareness, Mother was able to start sharing her grief, and in response, other family members shared theirs as well. Before Mother had married Father, Grandmother had told her that she had experienced the death of a son who shared his birthday with Mother. Through the years when Grandmother would call to wish Mother a happy birthday she would remind her, *"Today is also the birthday of my little Lawrence."* Now that Mother talked about her pain of losing Katrina, Grandmother shared her experience as well. *"As I learned later, she [paternal Grandmother] didn't come [to the funeral] because that would have taken her way back. And she still never talked about or dealt with that. And all of a sudden. . .it would have been about, maybe a year and a half after Katrina died. She shared the experience with me when I first married into the family. . . .She shared the death [of her son] We knew all the details of the death, but not what she felt. It was a year and a half later, when I was myself again, and on one of my mini retreats, and recharged. And I just said, 'I'm not getting over it, but I'm thinking I'm supposed to be.' Because, at the time, you're still getting these, 'Well, you'd better get over that,' messages. Time to get over it. Others would say, 'She's showered. She's good now.* She's finished. *She's through with it.' And then that's when she said, 'You're trying to get somewhere that doesn't exist. There is no time limit. It's gonna be a part of you.". . .And the words ring true, because it's forever a part of you."* With these words from Grandmother, Mother and was able to realize that the loss of Katrina required change and adaptation for her as an individual and for her family. *"All I remember is [thinking], 'Other people are doing this. This is not exclusive to you. You don't own this madness, so work on it. There has to be something you do to work on it.' And then, one of them [from the bereavement group for parents] explained to me that it's a journey. It made sense. But I still had this feeling that you get somewhere. . . .A journey is from A to B. After my mother-in-law straightened me out on that point . . .I thought, 'Oh, it's a journey that you carry, that you go on, but you carry, because it's hard for you to move on.' . . .And that was it. I came home and still struggled, but I wasn't scared any more. . . .And, that's when I knew I stood a chance. I knew I was going to be okay. I knew I had a lot of work that I had to do, but the blackness wasn't as black. . . .It was sort of foggy. And then I started noticing the distance between the bad days was a little longer. And then I just traveled. I just kept going through the hard times, but knowing I would get back up."*

With this realization came change that all members of the family recognized. Mother recalls thinking that for the girls it appeared that, *"Mom's home! Mom's back. She's gone a little bit, but she's back. . .I could do more on a daily basis . . . .It happened in pace with the return of my levels of energy. As my energy increased, I was able to see things differently. . . .And not as much deep, open, wailing crying. And not as much down time with no physical strength. So we got through, doing the Home Schooling with Sister 1. And then I went back to work. . . .And that was another turning point, because they paid me to exhaust my brain all day. I'd fall asleep because I was tired, I slept. . . .And for the first time, I'd hit the pillow at night exhausted because of something other than a broken heart. So that was another turning point. [The job] just happened. It's one of those things you don't question. . . .It just happened when it should have happened."* Family routines changed as well. Mother states, *"Sister 1 was born an old soul. She's been independent forever. . . .And she kind of liked the idea of a little more responsibility. She went back to school in the Fall of that year. . . .I think she was sick of me by that time, actually, and just welcomed the idea, anything that might get us back on track."* But the greatest change was that, *"Father and I decided that they wouldn't grow up in the shadow of Katrina's death, that we just had to get it together and move forward. . . .It wasn't going to be a sad place at all. And it wasn't going to be all. . .all about Katrina."*

At one point, Mother feared that she was not the same mother to Sister 2 that she had been to the other girls. She laughingly recalls, *"I was drowning in guilt because she [Sister 2] didn't have the same mother her older sisters had. I read to them religiously and took them to all the kids' concerts. I did everything with them. I never read to Sister 2. So, anyway I felt that it was particularly my fault because I never read to her. And I thought, 'I can't live my life in guilt, so I'm just going to make one big bang and get the guilt out of my head."* She planned an elaborate surprise outing to which Sister 2 remarked, *"Wow! That was so cool!"* Afterwards, Mother told a friend about the outing and its reason. *"I said I just couldn't handle the idea that my youngest didn't have the same mom and the guilt was killing me." And she said, 'What are you talking about?' And she had all these photos of all the stuff we did as families, when the kids were little. And she said, 'Look at the surroundings: your house. You planned everything.' And I had totally forgotten. . . .I couldn't remember. See, I had no short-term memory at all. And it was then that I thought, 'Okay. We'll, we'll be good. We'll be fine."*

Their family was restructuring, *"We were all messed up because we were 4 instead of 5. . . .And we just decided to do things that made her part of it, without making her everything."* They set upon the task of remembering Katrina, to bring her spirit home, *"Any time we had an event for them, we had helium balloons. And at the end of the event when everyone was gone, like their birthdays or that, we'd go out the back door. We'd write her a little note and tie it to the ribbon and send them off to her. And [when] some of Sister 2's friends were here. . . .They would say, 'Well, we're not leaving until we get rid of those balloons. We want to do that too."* Even their extensive network of aunts, uncles, and cousins remembered Katrina, *"She had a little grace she learned. . . . We always said her grace. And then it became every family dinner, no matter who was there, we'd say Katrina's grace. . . .And it's funny when we're with anybody, as a family, we sit down and they start Katrina's grace, without any prompting from us."*

Mother recalls early on, *"When we moved here, on top of their closets I had a sweatshirt of Katrina's: one on top of each closets because . . .I don't know why. . . .And I don't, you get to the point where you're doing these crazy things. But you realize that: I need to do this. . . .It's probably crazy and I don't care because I'm not going to tell anybody, but I feel that she still belongs because one of her sweatshirts is in each of her sister's closets. You know and it's just things that work for you . . .[then] you don't have that need. . . .Needs change completely."*

Over the years, the family has kept reminders of their life with Katrina, *"We just keep, well those little things. And I have some clothes I can't get rid of, so I'm going to make a family quilt. But I kept absolutely everything. And each year I purge. I look at some things and I don't want to keep them any more. And then I can get rid of more and more. The first year: nothing. The first 10 years: nothing. A piece of paper with a line on it: Love Katrina to Mom. . .I don't think that was going anywhere. And then you start purging and you have 10,000 of those papers. . . .Okay, kick in brain. Get off the side, heart. . . .And so now, I'm at the point where I'm going to make a scrapbook for each of the girls, of these things, these notes and little special things."*

One special way that the family chose to remember Katrina was a project in which they could give back the joy of this little girl who so loved Christmas. Mother remembers, *"And we asked them for an Inner City school. And what we would do for the last day before Christmas break, the week before, for two days we would bake and we'd make up these treat bags, and make little gifts and stuff for each kid in the school. . . .And then in January we'd get a thick brown envelope of thank you cards from the kids.*

Some of them were hilarious. This one kid said, 'Too bad your kid died. You make the best cookies I ever had.' . . .We did that for about 4 or 5 years. And we didn't have to do that any more."

As the years passed, the special events to remember Katrina became less needed by Mother and Father. Mother recalls, *"I thought 10 years was the turning point because it was a new measurement of time."* Throughout the time, Mother's brother was *"amazing. He has been with me every step of the way. He never misses an anniversary or a birthday. . . .When they were sweet 16, he gave them pink roses. He got a beautiful big motorboat. He said he got it on account of his anniversary. . . .He christened it, "The Katrina." It seemed fitting that at this turning point he too should be included, so Mother 'had a nice ceremony out on the lake in the boat my brother had bought. . . .And we were there on her anniversary, so we made it in the middle of the lake, and Sister 2 was there. It was really very pretty.' She collected rocks. We were always; our house was full of rocks. So I got us each a nice colorful rock that had a meaning. . .I gave it to each of them; and then I had them throw them into the lake as a sign that we were going to let her go. . .And then afterwards, I was good, but they're [the girls] not. I found out that it's true that everyone does it at their own pace. . . .But it's funny how I didn't have that need any more. And when they said [the next year], "What are we doing for her?" I said, 'Well, it's your sister. You plan something."*

When it came time for what would have been Katrina's high school graduation, a friend of Katrina's who had been in steady contact with the family asked them to attend the graduation ceremonies. This young woman had a special place in the hearts of the Broders family. Mother recalls that previously, *"If C was around [when someone would say Katrina had died], she went crazy. 'Katrina didn't die. She's in Heaven. She passed away.' She thought 'die' was too harsh. There was a time about that she should have seen counseling. She took it really, really hard. And she DID have a shrine for Katrina, in her room."* So the family was pleased to attend the graduation ceremonies with her, *"We were just greatly blessed and I had a nice cocktail party for all of us, the two families. And I asked her mom, I said, 'Can I treat her?' And she said, 'Oh, God, yes. The mother of 4 kids; you can treat her if you want.' So we sent her, we got a manicure and a pedicure and her hair done, all that. And then it was so hilarious because Katrina, with Katrina everything had to be pink. When we sat down at the dinner at her Grad, no one had spoken to each other or anything, but we all had something pink on."*

Through her many years of work leading groups for bereaved parents; Mother has found that, *"It's a real taboo subject still, to lots of people. . . .It's come a long way. But at some levels, it is. It's personal to some."* But this work has also, *"been a measuring stick of my progress, because sometimes I look and I think, 'Oh, I've been there! And I've been there. . . .Oh, I've been that raw. And I've lived. . . .You know sometimes I think: how can I tell these people what lays ahead?"*

"And I always say, I learned more from a 6 year-old dying than I could ever learn in life because. . .I do things I would never have done before." Mother does public speaking to many groups about her loss and grief as a way of honoring her daughter. She says, *"And I always call this; I always say I gotta do something for Katrina again. . . .I would never have done so many speaking appearances. . . .The only thing is, it's been such a journey that I feel a deep obligation to share whenever I'm called upon, because I don't think it's of any value for me to have learned what I've learned without passing it on that somebody else might benefit from. . . .She brought me these lessons. I think, in a strange way, too, I've been able to . . .give them strength that they didn't know they had."* Mother has also learned that each person must find their own meaning, often through the work of family sharing and meaning making.

She has found a special symbol of this experience, but relates how this symbol must be of one's own creation. Mother received gifts of angels from thoughtful people, often after speaking to the groups, *"It was their way of saying, 'I'm thinking of your broken heart."* And after receiving and displaying these gifts, she realized that others were getting the message that these little angels had a meaning for her which in reality, they did not. After about eight years Mother realized that she needed to put them all away because, *"the more I had them out, the more people were buying them for me, but it had no meaning to me. . . .So I had to somehow send a message."* However, Mother does have a special symbol for her experience, *"I collect Inukshuks because, for the simple fact of what they symbolize; that they symbolize a marker of finding your way. . . .And I think that's how I can describe this journey. I have been slowly finding my way at each point. Inukshuks were, are put up for Arctic travelers to know: you're on the right path. And I've looked at the whole journey as a number of turning points that have said to me, 'You're on the right path. Keep going.'"*

But mother has also learned, in her work with bereaved parents, that we bring to grief who we are and some of it is *"not all perfect . . .It's human. . . .And they [bereaved parents] can be cruel too. . . .But the basis of who you are is still there. . . .And if you had* *issues before, you still have those issues."* She has had to be patient and realize that. for some parents, enduring their anger and frustration in the group is necessary. Often these strong feelings cannot be shared with family members and space cannot be created within the family circle for these strong emotions. Mother hopes that when bereavement groups can provide a safe and controlled place where these expressions are tolerated, bereaved parents can move on to face their pain and heal.

Mother has learned that grief *"can come to the surface at any time. . . .some little thing can trigger it, some big thing, and then it can be latent for years, just there. . . . She's [grandmother] very right."* Unfortunately, in the last year Sister 1 was critically injured in an automobile accident. Mother experienced *"a very serious identity crisis because I felt guilty that she was. . .in trauma [not dead]. It was a very strange feeling, a very, very awful feeling. My identity had been shifted again. And I had just mastered [it]. . . . You know the newness. . .and now, who was I again? You know, I knew I was the mother of two children and one in Heaven. . . .It was crazy. All the [bereaved] parents that I know, their faces were just flashing in my mind every time I closed my eyes."* But when her network of bereaved parents heard of Sister 1's injuries, *"Those same people sure set me straight, thank goodness [laughs] just rallied around like."* She found their kindness acts again allowed her to face the new challenge and pain and adapt to it.

Of her family today, Mother recalls, *"My four . . .we were strangers in a foreign land, with a strong memory. And every now and then we'd pull a memory out and make it part of now. Pull a memory out and make it part of now. For quite a few years, we were that. We were where we would have been, but missing one part of it. But otherwise, we were back on track. . . .[And] when I talk about some of the people who did some of the things with me, I don't feel I'm talking through the sadness. I'm talking through the joy. There's people out there that love that purely."* She adds, *"We're blessed. Father and I have never been closer. I don't think there's been as much laughter through the house as there is now. I think from the time Katrina died; now the obstacles have been very trivial, in comparison. . . .And every now and then, when we're maxed right out, Father and I have our little routines, like sitting having tea, when it's just like BAD. Things are bad. And then we kinda just look at each other and, 'Bring Katrina back? No! So it ain't that bad.' Or he'll say, 'Well would you like to go back to the year after Katrina died?' And we'd both crack up laughing. 'No.' 'Well then, it's not bad at all.' And we're just re-focused, re-directed."* She summarizes her experience today this way, *"And then other* *times I think: it comes to the surface so fast that I find myself feeling the loss all over again . . .[and]I don't know if it's grief or. . .if it's true love."*

Summary

Revealed in the 13 family stories are a number of commonalities. The first is that the process during bereavement, both individual and family, takes time. It is a process that unfolds over a time frame that is unique to each family and to each family member. To describe the process of families during bereavement is to describe how each family, in its own unique way, addresses the processes that occur for both the individual family members and the family group. The families in this study do not reveal common stages reached at specific intervals following the death of the child; nor do they suggest a set time frame for an endpoint to their grief and mourning. To understand bereavement when a child dies is to understand that it is not only an individual experience but most often a family experience as well. However, this family experience may unfold in various ways within any given family.

The second commonality is that family bereavement takes work; work by each family member and work by family members as a group. While there is no specific formula or time frame for the family process during bereavement, this study found that there are common features, that when present, assist individuals and families to cope and allow them to live their lives without the ongoing, earthly presence of their beloved child. Individuals and families can be aided or hindered in this process by their previously held beliefs, attitudes, and patterns of coping before the death took place as well as by their family norms including their communication and shared beliefs. Stroebe and Schut (1999) suggested that the process for individuals is dynamic; these narratives suggest that the process for families is also a dynamic one. In this process, families quiet; they reduce activity both within and outside the household, as well communication between members may be reduced. Families tell the stories, share rituals, and make meaning in the life and death of the child that serves to create the child's ongoing spirit. This spirit will be carried forward not only in the present generation of family but also may be carried into the future serving to define "who we are as family."

The third commonality is that family members work together to lend support to one another by creating a space for grief and mourning, and engage in acts of kindness and love. These experiences are rooted in their family norms, roles, routines, and belief system (which I term antecedents) before the death took place and in the events that surrounded the death.

The narratives provided in this chapter demonstrate how family members bring together their individual experiences together with those of family to describe and understand their experience following the death of a child. However, it is important to note that these narratives are influenced not only by the family antecedents, but also by who contributed to the narratives by way of the interviews held for this study. In chapter 6, I will discuss the culture of bereaved families and their membership in an 'exclusive club.' The visual representation of the family process during bereavement depicted below will be further explained in chapter 6.

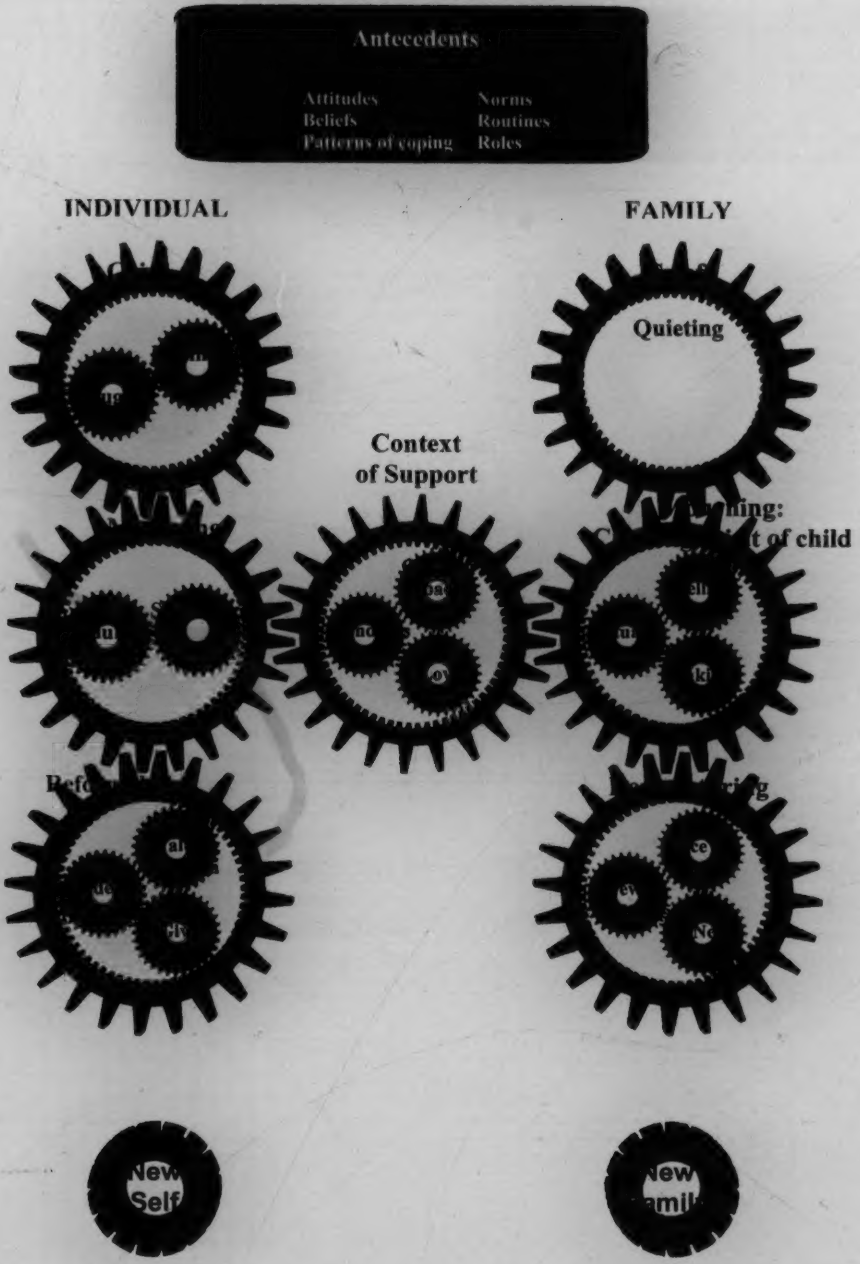
Antecedents
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Figure 1. Parallel process during bereavement following the death of a child

CHAPTER 6

FINDINGS FROM ACROSS-CASE ANALYSIS

In the last chapter I described, utilizing a within-case analysis, the individual and family processes of bereavement following the death of a child. In this chapter I describe the culture of the bereaved family, discuss the term bereavement as it is used by the participants in this study, and describe how family members work together (when they did) following the death of a child as emerged in the across-case analysis. 'Family work' is a central theme and I will describe how families work as both a social group, wherein they undergo a shared process during bereavement, and as a context of support for family members' individual processes. However, as seen in chapter 5 families described different and unique trajectories. Not all families engaged in 'family work' as a social group nor experienced a context of family support. As a result, finally in this chapter, I will describe how the process is different for individuals when the 'family work' is not done.

In this study, data analysis was an iterative process of across-case and within-case analysis. I chose to present the within-case analysis first in order to give the reader a view of the interaction of individual family members and how they together experience family bereavement. However, the construction of these narratives (chapter 5) required the across-case analysis and construction of the ethnography of family bereavement which will be presented in this chapter.

The Culture of Family Bereavement: Membership in an Exclusive Club

The families in this study clearly expressed their view that the death of their child placed them in an exclusive club. This view was expressed most clearly by Father Smyth who sat silent and crying softly throughout the family interview. He spoke only at the very end of the interview, saying,

> *Unless you've gone through it, you don't understand. You still have the same feelings but you don't understand. . . .People who have gone through it before can understand. . . . well, like with Grandma, right? Because she's lost two. And there's an advantage to all that, because you have a special bond with people who have lost children before, right? It's like you have a fraternity, where you don't have to say nothing because they understand.*

Club membership, according to the families in this study, was limited to those families who had experienced the death of a child. One family member spoke of attending a group that included people who had experienced a variety of losses. She found it difficult to link the experiences of group members to her own situation and was relieved when another parent who had been bereaved of a child offered to introduce her to a group more suited to their situation.

> *I'd go to Bereavement groups and it was all about loss of spouse, loss of income, loss of sexuality, loss of this, loss of that. And I'm mentally drained because this does not apply, this does not apply, this does not apply. And I'm thinking, "It's good to know I'm completely on my own." No one's feeling this; no one's experiencing this. This must be the onset of madness. . . . (Then) this dad stood up and said, "You know, respectfully to all you've said here, however, it's nothing like losing a child." He said (to me later), "I found a group. . . . Why don't you and your husband come?" And (when) we went to out first meeting, I was just mesmerized because I thought, "Um, I don't know how these people know this stuff that I've been writing about in my diary.*

When my participants had the opportunity to meet with other bereaved parents, there was instant recognition that they belonged to the same 'club'.

> *(In the group) All of our children passed away from different circumstances. And, I don't want to say comforting, because it's not comforting to know that somebody else's child died, too. But it is, I guess we put it, one time that we're all in the same club. . . . And it's the crappiest club in the world, but we're all in it, so when one of us speaks of something, the others go, "It sounds just like me talking.*

The culture of bereaved families is evident when "members of the club" meet and particularly when they gather in support groups. At times, however, bereaved family members meet each other in chance encounters. One father spoke of chance meetings with other bereaved family members.

> *When I'm at the coffee shop, somehow the conversation leads to (children, including Mateo)…the joy of memory. I don't go and tell people, "You know I lost a son." . . . But if the conversation goes that way, I can say, "You know, I can relate. Do you mind me telling you a little bit about the loss I had?" . . . It's always a joy for us to talk about him, even today.*

This familiarity speaks to two aspects of culture-- shared experience and shared language.

Being a member of the exclusive club can be deeply isolating; "*It's a real taboo subject still, to lots of people. It's personal to some."* This taboo made it difficult for bereaved parents to find each other since there is was no common geography or location (as is usually true of a cultural group) of bereaved families that allowed them to easily identify each other.

Following the death of a child, family members quickly became aware of their changed status in society and, over time, the space it created between them and their friends. Parents told of experiences where acquaintances ignored them. Even people they had thought were good friends shunned them. Parents said: "*I have no friends left that will help me with this.*" Siblings, too, reported a feeling of separateness that the loss of a brother or sister had brought, making them unable to connect with their peers in the way they had before the death occurred.

> *I cut off from my friends, for sure…you found out who your friends were. But you know some of them were really close before it happened….And then all of a sudden, they'd break off. I didn't really talk about grieving that much, though, with anybody other than my family It would have been hard, really hard. . . . your friends kinda on the shaky edge, saying, "You know, I don't know what to do with you." . . . I didn't want to go back to my friends, because my family really turned into my friends. . . . They were rock solid; we were so close.*

In this case, family became this young man's friends.

Abandonment, however, was not limited to friends, but occurred within some families as well. For some bereaved individuals, their own family members were unable to understand the experience and shied away from them as a result.

> *But it was really odd. . . . It's almost like they were afraid of me. . . . They wouldn't sit with the family at the funeral. They sat in their own pew. Like they thought, it's not like a grief they wanted to share. They didn't want to be part of it.*

Family members reported that they also learned that they needed to be sensitive to another person's willingness to engage in talk about their loss. In these cases, the family members did not abandon the bereaved individuals, but were unable to listen to mention of the deceased child or the experience of bereavement.

> *You can tell who is willing to listen to you or who will change the subject and move on and a lot of people change the subject and move on. (Others) didn't really talk about it at all and so I didn't.*

Even when friends are available, some participants reported feelings of isolation. One Grandmother found that sharing the experience of her bereavement was too painful to speak of even to a long-term friend whom she had placed in her 'circle of people resources'. Although this women had friends, she felt isolated because she was unable to talk about what she was feeling.

> *We (friend who she's known over 40 years) don't see each other too often (due to distance) but we talk on the phone or email at least once a week. I probably wouldn't call anyone (including her) if I was having a bad day.*

Unfortunately, these experiences of abandonment and isolation can occur even to bereaved individuals who reach out to members of their social network. This form of abandonment was particularly painful at a time when bereaved individuals had little energy to ask for support, an act they had not thought would be required.

> *There was a couple of times where I'd call somebody up and say, "Hey, I really need to go out for coffee?" "Oh, I'm sorry. I'm busy. Can we make it in two weeks?" And I'd be like, "Okay." (but) I was just kind of taken back.*

Sometimes the work of reaching out or helping others understand was too difficult for bereaved individuals. In these cases, they dropped their friends. Their social network became reduced when the bereaved persons let their friends go.

> *I don't talk to most of my friends any more. (We) just kind of went our separate ways. And I was going through this stuff. And they have their lives, too. . . . And I don't want to spend time explaining it (grief) to them. . . . The feeling or what I'm feeling. Space is created by this experience. . . . I think it's so hard to explain to somebody, a few people will say to me all the time, "I just can't imagine what you're going through. I can't imagine what it feels like." I (reply), "You just can't imagine it. I don't want you to.*

Not all changes to the social network resulted in its shrinking. Participants talked about the abandonment of some members of their social network and support by others. *"You lose friends and you'll be surprised at the people that offer you support and the people that just disappear."* Another participant put it this way, *"Some friends will come and some friends will go."*

When bereaved family members were able to find another "member of the club" there was an instant connection in which few words are needed. In these cases, the social network was expanded.

> *There had been a few different occasions over the years where somehow in the conversation I somehow figured out someone has lost a child, and that there has been an instant bonding with them and sharing of stories. The one that's most recent in my memory is a guy who would be in late mid to late 30's. And he was in a program with us in church last year and we just got talking about life and he mentioned that they had lost a baby at 11 days. And what an impact it had. . . .we ended up becoming very close because of that shared thing.*

Further, these connections give a long-lasting bond of acceptance, friendship and support.

> *The one couple (from a support group) came to court that one day, and you could have knocked me over with a feather to turn around and see them in the*

> *courtroom there. . . .I might say that when the group ends, I hope those bonds don't end. And I don't think they ever will.*

While bereaved families are geographically dispersed, it is this sense of shared experience as an exclusive club, often with a sense of distance and difference from others that define families who have experienced the death of a child as a cultural group.

Understanding Family Bereavement

Understanding the Term Bereavement

In Chapter 1, I offered a definition of bereavement as distinct from those of grief and mourning. I wondered, though whether these terms, which are so clearly delineated in the thantology literature, are used by bereaved persons in relation to themselves and so I asked them to define the three terms: bereavement, grief and mourning. I begin with their responses to my request to define bereavement. All participants in my study found bereavement a difficult term to define in relation to themselves. It was not a term that resonated with their experience. *"I never went through bereavement. I think that I mean it's a term that other people probably use to describe someone who is experiencing it I think."*

If participants could recognize the term bereavement at all, most commonly they described it as a "state of being" that occurs once death has been experienced. Participants saw it from a more emic perspective; *"You're a bereaved person because you've lost somebody. You're now surviving without them."* This definition is remarkably consistent with that found in the bereavement literature, reflecting as it does, the state of having lost a person close to you through death.

Other participants,however, offered definitions of bereavement that were less consistent with those found in the literature. *"(It's) past tense. . .what you've gone through and the ways that you've handled it."* Another participant said:

> *And bereavement, I would kind of put as something which to me is an ongoing form of life that even though it lessens certainly as you go on. I'm still feeling…I'm still in a bereavement stage about Helen's death…it's 27 years now and there are still thoughts for her.*

These definitions suggest a view of bereavement as a process rather than simply a state.

When the term bereavement was used spontaneously in this study, it was typically used as an adjective – "bereaved", to describe their social status as "bereaved mother" or "bereaved father". (In this study, only parents used the term 'bereaved'.) Some bereaved parents pointed out with some distress that there is no counterpart for "widow/er" and "orphan" in defining the social status of parents who lose a child and they believe there should be a special term to designate this unique and powerful loss.

Grief and Mourning

While the terms "grief" and "mourning" are clearly delineated in the research literature, participants in this study suggested that for bereaved family members "*They're all synonymous.*" Adding that the words speak of "*the process that you've gotta go through. . .after the death.*" It was impossible for family members to clearly differentiate the terms from one another. It may be that in the midst of the experience following the death of a child one goes back and forth constantly in the process making it impossible for the individual to distinguish between feelings and thoughts (internal process referred to as grief) from behaviors (external expression referred to as mourning). As one participant described it,

> *I went to this conference and they apparently are two different things. I think grief is instant and mourning you kind of get into it like I mean once your child passes away, you go through a period of mourning but the grief is instant and it could be there anytime. And you can get over the mourning period but you (go) through a lot of grief. So grief is intense and mourning is like a day-to-day thing that you kinda go through.*

In summary, the definitions of bereavement, grief and mourning are useful in the literature to distinguish the state (bereavement) from cognitive and emotional responses (grief) and behavioral responses (mourning). However, the terms have little resonance for bereaved person with the exception of the term "bereaved parent" which allows them to define their status of having experienced the death of their child.

Family: Description and Antecedents

Who Is Family When the Death of a Child Occurs?

When I spoke with the family spokesperson in preparation for setting up the family interviews, I asked the spokesperson to decide, with their families, who was to be included in the family interview. I asked the spokesperson to include any/all family members that they believed contributed to their experience of bereavement as a family. Various family constellations resulted. Some families included members residing in the house (including parents and siblings and in one instance grandparents) and those residing outside the house (including grandparents, aunts, uncles, including those not related through blood or legal ties which I have defined has "family of choice"), while others limited participation to only those residing in the house. This range is demonstrated by the Smyths where Mother, Father, Brother who lived in the house were interviewed together with Grandmother, Aunt M, Aunt P, Aunt and Uncle Choice who resided outside the house. In contrast, only Mother and Father Jones were interviewed as they believed that their experience as family during bereavement was limited to just the two of them. At times, family members considered important to this experience were either not available due to geographical distance or were asked to participate and declined to do so (most often stating that the death was too painful to discuss). The decisions made by family members regarding whom to include in the interviews offer insights about whom they included as family member during bereavement.

In a further attempt to understand how family defined membership, I constructed genograms with the families in the first interview. Initially I believed that the use of genograms would allow me to understand who was family following the death of a child. However, even when family members were asked to include on the genogram people who were considered to be family but not connected by ties of blood, marriage, and adoption, it was rare that families included family members of choice. It may be that the structure of the genogram itself limited family members thinking to only those members connected to them in these traditional ways. I realized this limitation after interviewing the first six families. Subsequently, beginning with the Myhres, family members were asked to draw their "circle of people resources". Once the circle was created, participants were asked to circle the people whom they considered family. They were then asked to define family and to explain why they had circled the people they did. Great variation was found through this process and the range is exemplified by the definitions given by Mother Schmidt and Brother 1 Damant. Mother Schmidt primarily included family through blood and marriage, with the exception of one woman she referred to as "cousin". This "cousin", although unrelated to Mother Schmidt by blood or legal ties, had lived with the family for most of Mother's childhood years. Although she lived at some distance, she remained in constant contact with the family. When asked to define family, Mother Schmidt included the "cousin" because in her view, families are limited to those relationships that begin in childhood and would be expected to carry on virtually forever. *"So, to me, family would be, [my 'cousin']that I grew up with, and my immediate family. . . .Father's family, too. . . .I've known them for 20 years. . .*

.Everybody else is friends." Mother Schmidt did not include very close friends whom she had known for many years, who had travelled to Georgia and who had helped to plan Mateo's memorial service. Despite their support and effort on behalf of the Schmidt family, their relationship was not deemed to be life-long and this is what precluded their designation as family. In contrast Brother 1 Damant defined family during bereavement as all those who *"help you in any way you need it and who understands what you're going through."* For him this included connections through blood and marriage together with friends and even his teacher. Other families described membership as falling somewhere in between these two descriptions. These findings lend support to the definition of family described in Chapter 1 and suggest that a broad definition of family is relevant within the culture of bereaved families.

Family Antecedent: Rules, Roles, Routines, and Shared Beliefs

Families in this study were asked about their rules, roles, routines and shared beliefs prior to and after the child's death. I termed these antecedents. In the process of analyzing participants' responses, it became clear to me that these antecedents to the child's death influenced the work that families engaged in during bereavement. When families had commonly held beliefs, an ability to communicate with one another, maintain flexible routines, and shift roles and boundaries, they were able to work together to meet family and individual needs. The importance of antecedents is most clearly exemplified in the deJong family story where antecedents were helpful in their experience of bereavement and by contrast in the Baker family story where their antecedents impeded their work together.

Norms (Family Rules)

Some family norms flow from an individual's family-of-origin.

> *Mother:* *My parents are very independent people; and they like their. . .independence.*
>
> *Father:* *It's something that she gets from her side of the family. . .they're very, very stand-offish. . . . (And as a result) she (Mother) just seems very, very cold (at times when he needs her comforting.)*

Others' norms were established early in the relationship between the couple.*I just think of the day after Father asked me out; I sat him down to talk we were pretty open at that point (and have continued to be).*

Some families made a conscious decision on how the family would work together.

> *I always worked really hard to try make us a strong family. . . . I wanted to give my kids a sense that we were a family and that we had roots and that we had traditions . . . . that we would stick together; and that I would always be there for my kids, no matter what. . . . We always have our Sunday dinners . . . . Christmas has always been sort of an important time and we have our traditional things that we make. And this year, I have to set the norm of what's normal for my family (since Ray's death). And it was important to Ray, before, in the hospital he said, "Mom, where are we putting the tree?" . . . And so, I wanted to make sure that we carried on with Christmas like we always did.*

One bereaved grandmother recalled the death of her daughter many years prior to the death of her grandson. At the time of her daughter's death, her mother had given her advice that she had decided not to take. The great grandmother then repeated this advice when Ty died. But grandmother had already changed the norm and the family was able to talk freely about Ty.

> *It was about 6 months after, it was my cut-off point. . . .My mother told me to put my grief in a box and put it in my pocket. And I said I can't do that. . . .(So) we talk about him every day.*

No matter how the family arrived at the norms that guided their functioning as a family, these rules formed a basis for how they interacted with one another after a child dies.

Roles

There were various roles evident within families. Some roles, linked with positions in the family (parent, grandparent, brother/sister), are determined by biological connections whereas others resulted due to the family members' attributes and skills that contributed to family functioning. When family members experienced flexibility in their roles, especially during crisis, family functioning was optimized. I will use examples from the Myhre family to demonstrate how family members took on roles and how the flexibility of role taking assisted them following Ray's death. Sister said, *"I think, depending on the situation we kind of change roles."* She recognized that during bereavement that meant that she could go from being "*the opinionated one*" to holding her thoughts when needed and becoming "*the peacekeeper*." Considering other family roles, she added that her husband was the "*calm centre in the family*" a critical role he had held before and that continued when Ray died. Sister also told us of Ray's role prior to his death. *"He was just kind of the center, without doing anything. He was always the one that never caused trouble, always in a good mood."* Sister and Mother commented on some roles that did not change a great deal. In speaking of Brother, Sister and Mother said:

> *Mother:* *He continues to struggle (due to his mental illness). . . .With Brother you have to be sort of careful.*
>
> *Sister:* *I see how hard it is for Mom since Ray passed away, and when he (Brother) makes it harder, that puts a strain on all of us. So it's difficult for me sometimes . . .because he can be ill. I (try to) keep the peace. . .between me and Brother, for Mom's sake. . . .And I'm trying to be understanding. It's just Brother and I have a previous history of not always getting along well. And I almost feel like I mother him a lot.*

Roles can add complexity to family work as well. In the case of the Mhyre family, Stepfather joined the family just prior to Ray's death. While Mother saw him as playing a vital role in the family, saying, *"He loved Ray. He loves me. He loves my family. And he's a wonderful man."* But Sister struggled in her relationship with him and in her perceptions about the role he plays as part of the bereaved family.

Beliefs

In some families shared spiritual beliefs aided them in their work during bereavement. This may include a belief in the ongoing presence of the spirit of the deceased person, manifested in the form of visions and dreams.

> *And Niece has seen him (when she was four years old). She came and she said, "I saw my uncle out my window." She said, "He had blue wings. And he said, 'Give me a kiss.'" And her story has never changed.*

Other families had more traditional religious beliefs that guided their work during bereavement. *"God's gotta have a, a plan. And I think we thought that whatever His plan is. . .if that is Hannah's purpose, whatever it is. . .to open up doors, or whatever. that we would follow. . .and do that."* Whatever the belief system, as long as they were shared, the families were able to use them to help them with their work during bereavement.

Family's norms, roles, and beliefs formed the antecedents for how family members worked together following the death of a child. They formed the basis for how family members communicated with each other and how the boundaries were formed that allowed family members to support one another, guiding the work that was done by families during bereavement.

'Family Work' During Bereavement

The main purpose of this study was to describe and understand the experience of families during bereavement following the death of a child. While conducting the interviews I realized that families were talking about the work they do during bereavement in two distinct ways. First, there was work that the family did as a group – work that was shared and that was of benefit to the family itself. Second, there was work in which the needs of an individual family member were supported within the context of the family. When family was context, the individual family member focused on his or her own needs and was supported in this endeavor by the family.

Family as a Social Group: Working for the Benefit of the Family

When families worked together for the mutual benefit of all family members, common processes were seen. Families showed variation in their emphasis on the processes and the process for each family had its own time frame. However, the processes had common features and these will be discussed in the next sections. These processes included quieting, creating the spirit of the child, and family restructuring.

Family Grief: Quieting

When families spoke of their initial responses following the memorial service for their child, they almost invariably spoke about reducing family activities both inside and outside the home; about becoming quiet as a family. This process occurred in 12 out of the 13 families in my study and is best exemplified in the Damant family story. I refer to this process as "quieting". It occurred to me that this quieting was an internal experience of the bereaved family just as grief (feelings and thoughts) is referred to as an internal experience of the bereaved individual. Quieting may serve a similar function to the shock that occurs at an individual level. Just as shock gives the individual time to absorb his/her changed world, quieting appears to serve a similar function for families.

At times, families talked about the quieting in a way that suggested that it was their choice to do so.

> *There wasn't a lot of activity. . . .We spent time having suppers and watching television and going for walks and things like that.*

> *There was some relief when the Memorial was done. I think that was, for me, kind of a relief and just, to kinda sit back and just, "Okay we can just kinda do nothing". . . .And you're free to do nothing. Didn't have to plan for anything; it was just that part was nice, too. . . .And all of a sudden (it its), it was just her (surviving sibling). So that's much quieter. I had three months with (off work) . . . .We didn't go camping at all. . .every summer we'd always gone camping.*
>
> *The first summer after Sarah died we didn't really do anything.*

In other cases, the quieting seemed to be imposed on the family member and when it was, it seemed difficult for them to accept.

> *Before, I'd help out in the field with the cows and stuff, but (after Ben died) I didn't do that. I was trying to do a little bit of the housework and laundry and I just couldn't focus, couldn't do much. . . .Getting out of bed was hard and there's times I still can't focus or remember things. But you just wander from room to room. You know there have to be dishes done or laundry done or, or chores outside to do and you just have to force yourself to do them. . . .It was hard at home because it was quiet.*

Routines of the family inside the house were most often limited to just the essential activities to keep the family going. Even when families had been socially active prior to the death, they found themselves spending quiet time at home.

> *The kids loved to plan parties. If there's not a party in sight they make a reason up. We plan parties all the time. It's just that this last year's been really tough for everybody. So, we haven't been doing a lot. Which is weird because normally we make such a big thing of it. But this year, we haven't been making such a big deal about (anything).*

Quieting seemed to be limited to family members who resided in the household of the child who had died. In fact, family members who lived outside the household became busier as they worked to support the family members residing in the home (most often parents and surviving children). Their usual daily routines of work and maintaining their own households continued as they added on activities to support the family members living in the household.

> *I was always going over there and I would go on days off and spend nights, just to have somebody different in the house because it was very quiet for a while there.*
>
> *After Harry passed we'd go over there, like every Friday night.*

Not only did family members who lived outside the household reach out to those who lived inside it, family members outside the house also increased their contact with each another.

> *We phone each other more.*
>
> *Every once in a while because it's hard to get a hold of him (Brother who lived outside the household) on the phone, I'll just send him a little note. . . .And he, like many boys, (laughs) young men, he never ever responds, though.*

It appears that this quieting allows families to examine the needs of the group along with creating a space for individual grief and mourning. In this situation, Mother and Grandmother are discussing the current interaction patterns within the family.

> *Grandmother: We haven't done anything in the last year.*
> *Mother: And there's a point in every day where somebody's crying, or quiet or withdrawn or nattering a bit at each other and it's stressful.*
> *Grandmother: We're just kinda letting each other do it....Maybe there's a pat, or there's an acknowledgement or. . .Sometimes you look; sometimes you just leave them alone. . . .We do that a lot. Sometimes I'll just go sit outside, or sit in a corner, whatever.*
> *Mother: We're not really freaked out about that. That's normal (now).*
> *Grandmother: Yeah.*
> *Mother: I think I'm still in shock about it. . . .a lot. (Ty's death was). . . .My mind and my body might have closed off a lot to allow myself to get through it. . . .But it's been very hard for me, since he's passed away to get back to any state of normalcy in my life. My whole outlook on life is different. And my relationships with a lot of people. . . .Whereas I used to have a lot of friends and a lot of people I talked to. I was really social before. . . .And now I find myself more closed off.*

Mother demonstrates the connection family grief has with the feeling of the shock that is part of individual grief.

Father Stewart is the only participant who did not report quieting. His experiences differed from those of the other twelve families. He stated,

> *I set some goals and objectives to (move) closer to her family and my family...it's the way I got, or tried to get my life going again, to get re-focused on my business and my goals and my objectives and my dreams. . . .We'd written them out. I used to set goals every December and try and plan things all out for the year. . . .We did that that year as well. . . .We took a big holiday.*

His statement indicates how busy he and his family were both before and after Baby Lawrence died. Since Father Stewart was the lone Stewart family member interviewed, perhaps quieting occurred of which he was unaware. Father Stewart's alcohol intake suggests that he was trying to avoid the pain of grief. As has been suggested in his family story, Father Stewart attempted to deny his individual grief and perhaps in so doing he also denied his family grief.

When I first conceptualized this study of family experience following the death of a child, I believed that although individuals grieve and mourn, families cannot grieve. They can only mourn. I believed that the only component of 'family' that would be evident would be their behavior. Hence, I thought of this as a study of *family mourning*—behaviours that can be observed following a death. During analysis of the data, I realized that bereaved families appeared to be grieving as well as mourning; that families had a tone – a tone that would be evident to any sensitive person entering the home. This tone was what I called 'quieting'. This recognition of quieting created a shift in my understanding of individual grief versus family mourning, to a conceptualization of both grief and mourning occurring at the family level. Grief and mourning are then part of family work during bereavement.

Family Mourning: The 'Family Work' of Creating the Spirit of the Child

In the Literature Review chapter, I described the change in bereavement theory from detachment to creating a continuing bond with the deceased child (Klass, 1996). In this study, the families described the work of creating this continuing bond with their child in three ways: They tell the child's story, they engage in rituals and celebrations of remembrance, and they work together to make meaning of the child's life and death. I refer to these three processes together as 'creating the spirit of the child'.

Family mourning creates an opportunity for families to create an ongoing place for the child in their family. When family members work together, a richer story of the child is created, one where family members are assisted in their individual work of grieving and mourning the child's death. But not all families engage in a shared process of creating the spirit of the child thereby engaging in family mourning. In this study nine families reported in rich detail how they created the spirit of the child, however, the four families where divorce occurred did not. In these families, creating the spirit of the child was done only on an individual level and did not involve the process of family mourning.

Creating the "Spirit of the Child" through Telling the Story

The stories family related about the child were focused in three areas a) who the child was and what s/he contributed to the family b) about the child's dying and death, and c) about the funeral/memorial service. In the process of listening to family stories, I came to see that the stories fulfilled two main purposes. First, telling the stories allowed family members to construct a history of the child within the family and served to create an ongoing place for the child within the family. Within this purpose, they shared details of the child's life that may otherwise have been forgotten.

> *Mother: Now I do remember something like that, now that you talk about it.*
> *Father: I'm providing stuff that you didn't remember and you're providing stuff that didn't remember.*

Second, telling stories allowed them to understand their loss within the context of their belief system. This latter purpose of telling the story is something I came to call 'meaning making', which will be discussed in a subsequent section.

Who the Child was in our Family

Telling stories about who the child is one way families tell the child's story. Family members told of their personal relationships with the child revealing the complex and rich fabric that made up their family. Relationships within the family are often interconnected. Families demonstrated how the similarities and differences helped to support family functioning.

> *We were both really close. . . .so it was losing companion, more than the big brother. . . .We were equals, but then, at some points, he'd go immature. And I'd have to buck up a bit and say, "No". . . .And in different ways around, I'd go immature and he would buck up and say, "Come on." . . .Sometimes when I got out of line, he'd come and tell me not to.*

> *Before Ray passed away, he made him (Brother) promise that he would be okay. . . .he said, "You know (Brother), I want to live so badly and I can't. You have to promise me to be okay." Ray was an exceptional kid.*

Family members who lived outside the house also had relationships with the child that influenced family functioning, as one aunt revealed,

> *We started having. . . .like monthly aunt and nephew days. And what we'd do was, we'd go for lunch and, and a movie and then supper. . . .I waited until they were older and my kids were older. And I was able to spend more time with them. I've always been more outspoken with my kids, too. I tell them everything. . . .I was the Aunt who would teach them everything their parents wouldn't tell them. . . .well not everything. But to a certain point. . . .And I joke with them all the time.*

The Dying and Death

Talking about the dying and death was another important aspect families told of the child's story. Often creating 'the spirit of the child' began with the stories of the dying and death as family members worked together to understand how a young life can be taken from them so suddenly. Sometimes this began with a recognition that the child, who had been ill, was now dying. For others, it was hearing about the moment of (sudden) death.

> *We saw them get off the plane, we were, both Ray's grandfather and I were both very, very afraid. . . .Because we could tell by looking at him, that it was a lot more than that. . . .And . . . .then of course, as it progressed, it was so terrifying. . . .And so scary. . . .And it made me so damn mad. . . .That somebody like Ray, who was so truly good. . . .Would have this horrible disease descend on him.*

> *Mother: She saw what happened on the slide. She can tell exactly what Hannah looked like on the slide when she had died.*
> *Father: Not really a happy or sad story, just, this is what happened.*
> *Mother: I always got a pit, like in the pit of my stomach it just, when she would say happened and, and how Hannah looked, it was just. . . .It was hard to listen to.*

Even many years after the child died, parents were able to recall in detail the events surrounding the child's death.

> *Helen was only sick for 9 weeks so it didn't give us any time to really get used to the idea that she was ill. And it didn't give us any time to get used to the idea that she was dying. . . .I was present when they did the scan and I could see this tumor in her head, and I know that nobody survives with that size of a tumor in their head. And of course now, 27 years later thinking about that denial, I realized I needed to be there. I don't think I had any capacity to cope with the kind of pain that resulted from her death. . . .Now I realize, and well I realized after a few months, was that all of my memories of Helen at that point were on the child who was ill. And even though it was only 9 weeks out of her 5 year life. . . .all I could remember of her.*

Discussing the Funeral/Memorial Service

Further, families told about funeral/memorial service as a way to tell the child's story. Funerals and memorial services served as the first way for families to commemorate the lives of their children.

> *I had a celebration of his life. . . .And it was beautiful. Because it really was a celebration of who he was.*

> *The kids that were in his class in grade 6. . . .one of the Moms ran a choir from that school and so she had arranged for the kids to sing part of the Service. And actually, she got a group of his former teachers to sing, as well, which was lovely.*

Time for Mourning: When Stories are Told

The work of family mourning may be done at any time. While some families began the 'work' of creating the 'sprit of the child' immediately following the child's death as family members gathered to plan the funeral/memorial service, others engaged in this 'work' after many years.

> *Hannah was a funny kid. . . .she could get into some real mischief, sometimes. So, sometimes people would say things and it would just be so funny. . . .And we would just laugh. I think we needed that. . . .And then we'd have a good laugh. And then we'd start crying again and. . . .we sat around a lot and just talked. . . .but at the same time, it was different. But it felt really healing to actually talk and hear other people talk, about memories of Hannah. . . .That was really neat, to hear other people. . . .what other people experience and how they feel. . . .Sister loves to look at. . . .old family videos. . . .She can spend hours watching the family videos.*
>
> *Every year on her birthday which is February 25, so the middle of winter, I get six balloons that are the colour of the rainbow and I take them to the cemetery and I tie them on a tree that, she is buried right close to a tree, and if I remember to bring a shovel. I always have to shovel the snow off the gravestone. And so I do that. . . .All these years I have gone alone, at least most years. But this year my little granddaughter is learning about family at school and she is trying to figure out how the little girl in the picture who is obviously younger than her can be her aunt. She has asked me about her and I have shared with her the funny things Helen would do. So this year Brother and his three children came to the cemetery with me. We tied the balloons to the tree, shoveled off the gravestone, sang happy birthday. It was nice to have it a family time.*

Figure 2. When stories are told

Siblings who were too young at the time of the child's death to understand what was happening in the family, processed the death as they moved through their ongoing developmental levels. In these instances, family mourning may mean recalling the child stories, watching videos, and looking at photos on an ongoing basis throughout the surviving children's development. One sibling told of the help she received to mourn the loss of a big brother,

> *They told me about how he'd scare all the girls with his shark gloves. . . .And, how he kissed a girl at school and ran home. . . .and things like that.*

Further, families demonstrated the power these acts of remembrance had in creating the ongoing 'spirit of the child'. As one sister recalls:

> *I think, if I didn't have any videos, or anything and I saw a picture of Mateo, and I didn't know what he looked like, I would know that he was my brother, because, like being with him, I think I would recognize him as my brother.*

The Use of Mementos

In this study, families referred to mementos they had kept of their child, often bringing them out to show to me who the child was. In each of these families, I sensed that the families needed to show the photographs to me. Of all the families, only Father Stewart had no picture or mementos of the child (although he thought his wife might have some items). In the homes of the children who had died within the past two years, the child's room was often intact. Some families used this room to grieve and to mourn; finding comfort in being near the child's things. In one instance, however, the room was kept locked and was considered off-limits to family members. In this family, the parents did not go into the child's room. For them, it seemed that the room was not a source of comfort. However, this family created a memorial garden where they were able to receive solace.

Figure 3. Memorial garden

Some families gathered the mementos into a box, which they brought out to show to me.

Figure 4. Box of Memorabilia

Mother Broder talked about her initial need to keep absolutely everything that had belonged to Katrina and that over time she was able to get rid of some items. She now has a plan for what is left.

> *We just keep, well those little things. And I have some clothes I can't get rid of, so I'm going to make a, a family quilt. But I kept absolutely everything. And each year I purge. I look at some things and I don't want to keep them any more. And then I can get rid of more and more. The first year: nothing. The first 10 years: nothing. A piece of paper with a line on it: Love Katrina to Mom. . . .I don't think that was going anywhere. And then you start purging and you have 10,000 of those papers. And so now, I'm at the point where I'm going to make a scrapbook for each of the girls, of these things, these notes and little special things.*

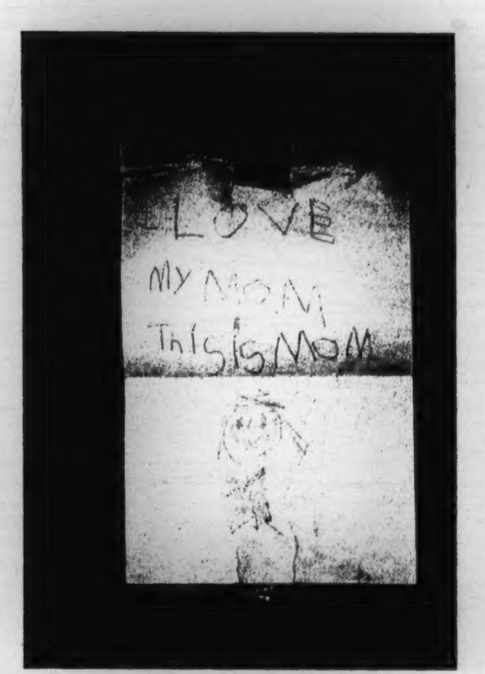

LOVE
MY MOM
ThIS IS MOM

Figure 5. "10,000 scraps of paper"

The items kept by families often symbolized who the child was. In one case, the child's athleticism is remembered through his bike helmet, basketball shoes and t-shirt.

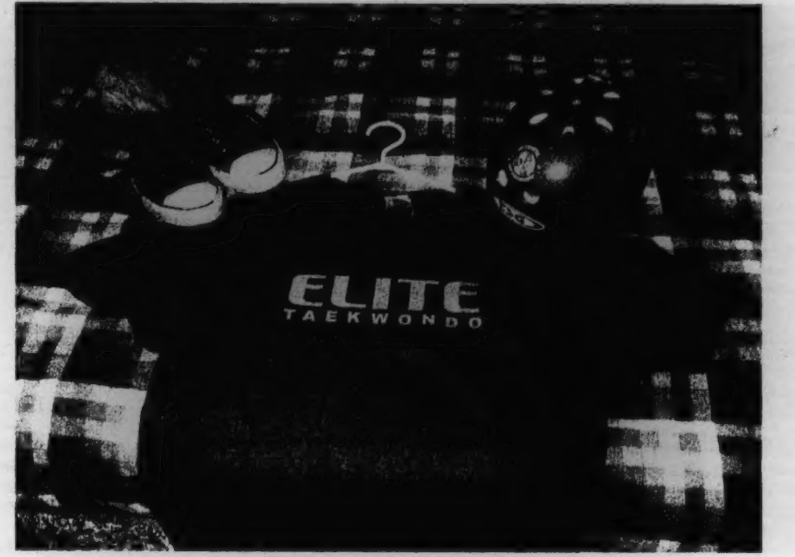

ELITE
TAEKWONDO

Figure 6. Memories of an athlete

Another family kept the specialized chair that allowed the child to sit up.

Figure 7. Remembering a child with disabilities

Sometimes families kept the arrangement of mementos, including the urn containing the child's ashes in a special bookshelf.

Figure 8. The memory wall (with urn)

Sometimes, a family member will make a special memento that is given as a gift to the other family members. This photograph shows a suncatcher that depicts the deceased child, now an angel wearing a ballcap. Each family member received a suncatcher as a memento of this child.

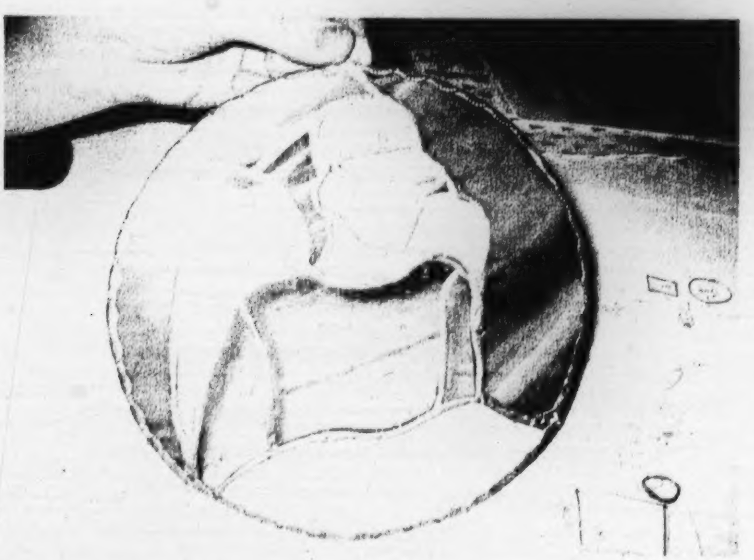


Figure 9. The suncatcher remembrance

Creating the 'Spirit of the Child' through Rituals and Memorials

The 'work' of most often began as families gathered to commemorate the life of the child at the funeral/memorial service. Family members who lived outside of the house were often very helpful with the many tasks needed to carry out these events. As well, they were instrumental in beginning to tell the stories.

> *We started planning the funeral. . . .And Father's sisters were great. They went and organized all the food. And my brothers were amazing; they got all kinds of wine. And we ordered 75 pink balloons to be delivered to the house.*

Grandmother: *She had all her friends take her to the funeral home and they just went and did everything.*
Mother: *We made arrangements to have Harry cremated . . . .When we were at the funeral home, and so when the gentleman was trying to force me to buy an urn, I said, "No thanks, I have one". And so we all just started giggling, because we all knew Harry's story about the cookie jar. So, we have his cookie jar here.*
Father: *We had tons of pictures . . . . (and) put together the slide show for the Memorial Service…as a group.*

Mother: It was neat, too, other people who were here, Father's brother and his wife and, and my brothers. They all were kinda saying the same thing, that they felt horrible before they came; and then just sitting around in this group, it actually . . . .they felt much more at peace.
Mother: We had a Celebration. And I involved the people who were important to him…his favorite teacher spoke. His Tai-Kwan-Do instructor spoke. The one aunt, "Sweet Auntie", she spoke. My dad spoke. And his friends were very involved. They got up (and) played music, they, spoke. It was, it was BEAUTIFUL. We did a slide show.
Sister: There was lots of laughing….And we had a big display.
Mother: We had a display. Sister did a beautiful display: pictures, mementos.
Sister: It was sad; but it wasn't.
Grandmother: We went back for his (pause) for the Celebration of his life….The first day before the Celebration and the day of the Celebration, there was a zillion people around. And so we mostly just reminisced….We talked a lot about him a lot….And it was a good family time.

Anniversaries of the child's birth and death were other occasions when families gathered to create the spirit of the child by telling the child's story. Rituals are important ways to remember the child, whether they involve activities or telling a story of the child.

On (his birthday) we all said no matter where we are, we all have to have soft ice cream.

Father: (On his birthday) the boys stayed home from school. At Ben's funeral, some people had brought things: an angel, and some of those solar lights and a few plaques. And our cousins bought the little boy, and he is knelling down with a bird in his hand, and got lovebirds and flowers, and he was a real, real nature guy and we kinda built a little garden in the yard. And the boys used to have their trampoline on the south side of the house. They played there lots. In one of the areas there was a nice place for that stuff. We planted a lilac tree
Mother: Our sisters even helped us with that. And we went to the cemetery and put in one of those garden stakes and hung up a flower basket we filled it for him. We all put flowers in the basket. And then we came home and had a bit of a wiener roast. And Uncle and Aunt and Grandma came over, and a cousin's boys came over.

We planted a big oak (after the memorial service) . . . .our family bought it for us, our families together . . . .We plant a tree every year, on that day (of her death).

Mother: We do a barbecue and invite a lot of our friends and family…
Uncle Choice: We release those damn balloons! (Laughter)
Aunt M: And that damn song!

Mother: *Josh Groben! Just a Breath Away. (Lots of laughter and some groans).*
Aunt M: *Everybody is having a fabulous time, all laughter, news, and joking and then she turns on this music…!*
Grandma: *And then they released the balloons.*
Aunt M: *Well! Tears come and everyone's down*
Aunt Choice: *And that's the end of the party so everyone leaves!*
Uncle Choice: *(This year) We weren't here this year. But we let the balloons go.*
Aunt Choice: *Yeah, we were in Manitoba and we let the balloons go. And I took a picture.*
Mother: *And you e-mailed it to me.*
Aunt M: *(Often) I missed it…but I always did the balloon, too….And then, it never failed, on that day, seriously, I don't know why, but his song came out "Josh Grobin" and we call it Harry's song….So it was like, 'I don't have to be there anyway, because he's here.'*

Families also found special ways to include the child in their family celebrations. These occurred at regular holiday times such as Christmas, but also for special occasions such as family weddings.

Mother: *We've have a tradition at Christmas. Just to remember the people who aren't with us. We light candles…Sparklers! I love stars-- five point stars. Because they remind me of our family. Not that there are five of us but our names all have five letters. And Harry's name has five, five points of the star. Harry is the star in our family. And I buy star shaped candles every year and we light the sparklers in remembrance of Harry and both dads, and anyone else.*
Aunt P: *One time I said a poem, at prayer time before our meal. (Paternal Grandmother) for Christmas, decorates the basement with stars. This Christmas, I gave Father and Mother a star light catcher for their window.*

Sister: *Ray had done some artwork. He loved to draw and paint. And Mom surprised me. She had a piece of his artwork framed for me. That was very important to me and my mom also gave me my cross for Christmas, because I always said I wanted a cross to symbolize him. And so I got that for Christmas….And there was an angel for Niece from Ray.*
Mother: *And every year there'll be an angel.*
Sister: *(Niece considers it) a fairy, because she always thought he was a fairy. She couldn't grasp the concept of angel. (I had told here) "Your uncle is in heaven now? He couldn't get better here. He had to go to heaven. But he's an angel now. You know he's always going to watch you.'…So she told everybody her uncle was now a fairy…. And we had quite a laugh (because) a few hours later, she comes, 'Mom. My uncle's, he's a fairy.' (laughter) And we could just hear Ray's voice, all of us, "I'm not a fairy!" (laughter)… So it's become something; it's a story. We can tell it and we can, we laugh.*

> *Sister 1 came to me and said, "Mom, this is what my fiancé and I have decided to do. I'm only telling you because it probably wouldn't be a good thing to surprise you". I said, "Okay". And she said, "At the altar, there's going to be a pedestal behind him and a pedestal behind me. And there's going to be a picture of Katrina and a candle and a picture of (his brother) and a candle, and a little silver bell. When Dad brings me to the altar, before the ceremony begins, I'm going to light (his brother's) candle. He's going to light Katrina's candle and they're going to ring the bell to bring them to the ceremony.". . . It was beautiful. And in her wedding pictures the photographer had taken a shot of both. And in her program I wrote, at the top, the significance of that. And ah, and oh yeah, and she had a pink rose there for Katrina's bouquet and a red one for (brother's) boutonnière. But it was interesting, you know, because we'd been sitting there looking at her and her sister together, and their arms were touching. And I could see the big hole where Katrina should have been.*

Creating the 'Spirit of the Child' through Meaning Making

During the family interviews, I noticed that family stories not only served to create an ongoing place for the child within the family (as outlined earlier), but in the process of connecting the child's story with the family's belief system, the families were actively engaged in the process of meaning making – making sense of the child's life and death, and coming to understand the value of this life that had been cut short.

When families worked together this was a shared process; as one family member told of their beliefs, other family members would comment, either confirming with their beliefs or modifying the beliefs with their own ideas. While meaning making was also an individual process, it appeared that when families told their stories of the child, each family member contributed his or her own sense of the child. By incorporating so many viewpoints, the child's spirit was fuller. Nadeau (1998) examined the phenomenon of meaning making following the death of an adult family member. She states "Meaning making occurs in families at all systems levels, from the individual level to full family process....Families settle on some meanings soon after the death, but others seem to evolve over time" (p.101).

> *Grandmother:* *We believe there's something better out there. Because if you didn't, it would be very hard to accept. So we keep thinking there's something better out there. And so we can accept it easier. And then someday we will be together again, if we keep believing that.*
>
> *Aunt M:* *All things happen for a purpose in life....I know we all want to be here forever, but we can't. ...if you can put those two together, like: don't be mad; just be happy for that person....So even the fact that for Harry it was such a short time. You're still able to put it in that place of saying: 'He had a purpose. And he fulfilled it.'*

Father: *God…He's the one that gives life. He takes it….And I had to just keep coming back and saying, 'Mateo left us at the right time and this was the life he was given.'*

Mother: *I'll tell you the reason I think why I had less problems….My dad; I love my dad. My dad is not perfect, but my dad loves me and he loves his kids. And he doesn't have favorites. And he's been such a good example to us. He's just a great man. But he's human. We know his faults, but he's still a wonderful man. And he always tries to do the best for me. But, if my Heavenly Father knows me better, and he took my son, then there must have been a reason that He knew that it was best….I trust my Heavenly Father because I know He knows me and He loves me better than my father….And so I see God as a father. Some people see God as a friend or a pal, or whatever. But I see Him as a loving, all-knowing Father….And because I could trust my dad, I could trust my Heavenly Father. And so I knew that there was a reason for it….Because we can't always figure out why God does what He does.*

Sister 1: *It (their sharing of their faith) definitely did….The whole time since Mateo died, we've been like, "We don't know why he died, but God does, right?" So we really can't blame anybody for it because it was his time to go."*

> *I think your spirit comes to learn that your life's lessons and, and if you need to learn more lessons, then you choose to come back….I believe that to be true. So, if Ty chooses to come back, that's going to be his decision. But in the meantime, I believe he visits us.*

The families in this study reported other ways of making meaning of the child's life. One of these ways involved fund raising activities. Sometimes these activities were done by only one family member, but most often numerous family members took part.

Grandmother: *She went on a mission and I think when you have a mission it helps with your…grief.*
Mother: *It gives you a purpose.*
Grandmother: *Yeah, a purpose.*
Aunt Choice: *And she did a good job there!*
Mother: *And Harry held the doors open! What happened… they put in a lot of red tape, for they had those little TVs there, those rental TVs for the rooms. And Harry felt that was unfair. So I worked really hard to cut through it. In Harry's obituary, I said that donations could be sent to the TV fund at the (local children's hospital). But at that time the TV fund didn't exist. It was coming. So we raised quite a bit of money. I brought the proposal and said this is how you're going to do it. And the money is coming. So now the kids have the TVs.*

Mother: *Father works quite closely with Make-A-Wish. He raised a lot of money with running.*
Father: *I didn't raise the money, Uncle Choice did. (Laughter)*

Uncle Choice: *I raised just half the money, you raised the other half. And you did all the work, I just solicited customers. And you did all those… running and biking.*

Mother: *Every person who is born is going to die. That is the way life works. But you're so scared. I'm not scared to die because I know I'm going to be with my son….He had so much to teach us. So, we've planted a tree for him at school….And we just started a Website for him. The school dedicated a cookbook to him at the end of the year. At the organization that had supplied all his caregivers, we asked to have a staff award in his name, in his memory. So that's something that will be happening this year. Last year we did a 12 hour (game) marathon. The (youth group leader of an organization Mother works for) spoke to his youth and they got the idea that they wanted to do something in memory of him, so organized an event. And this year will be our second annual and we're going to raise money towards helping special needs kids participate in recreation. Last year we raised over $2000 for (the local children's hospital….There's been quite a few things that we've done to keep him alive….We're doing Patrick's (game) (again) next month; and we've been planning for quite a while.*

Father: *(Since) she's decided that's what we're going to do: (I) jump on the bandwagon.*

Mother: *I get empowered when I take on projects . . . .it fills my time and it's something meaningful.*

As families worked to 'create the child's spirit'; through telling the child's story, celebrating the child's life, and making meaning of the child's short life, they created an ongoing place for the child in their family. By securing an ongoing place for the child, the family began to restructure their family.

'Family Work': Family as Context for Individual Grief

My findings suggest that families functioned in two ways during bereavement, as a social group as has previously been discussed and also as context to the individual process family members experienced following the death of a child. In my study, family as context during bereavement was about support. Family members supported one another through creating a space for the 'work' of individual family members and through kindness acts as well as loving acts. This 'family work' can occur even when there is little or no shared family work as seen in the Baker family story.

Creating Space

The families in this study created a space for the different grieving styles of their members. When family members recognized and allowed each individual to have their own way to grieve and mourn, relationships were strengthened within the family. This is best exemplified by the Jones family story. Further, observing others during bereavement may have helped to create an understanding of the importance of the child's life and his or her place in the family.

> *Father and I grieve differently, and . . . .we need to make sure that we're talking to one another and being there for each other.*
>
> *We're all different . . . .So the last thing in the world, which is probably doing this (interview), for Father, is probably the last thing in the world that he wanted to do . . . .Just the way he handles stuff . . . .But it's something, it's tops on Mother's list . . . .So that's why we're doing it.*
>
> *I spent a lot of time resenting Father because I didn't think that he loved Sarah, as much as I thought he should . . . .But I didn't give him credit for the fact that he just is so introverted, into himself and it took him a long time to be able to grieve and to admit some of the depth of his feelings. Because they are there. And I just resented him for such a long time, and then I just started to realize that was really dumb.*

Families created both physical and emotional spaces for their members. For some this was seen even in the family interview. Humor may decrease the tension and allowed family members the opportunity to compose themselves.

> *Mother:* *And we made arrangements to have Harry cremated. His remains are still with us. We haven't spread his ashes is. Some day. (Short pause, Mom is softly crying). We have them…*
>
> *Aunt Choice:* *In his cookie jar! (Laughter).*
>
> *Mother:* *There's a story behind that.*
>
> *Interviewer:* *Are you willing to share that story?*
>
> *Mother:* *Oh, for one Christmas we got this biscotti jar. It's down there. It's a beautiful jar! So Harry and I would tease each other, and one time he said "When I die, I bet you're going to bury me in that cookie jar!" So we laughed about that. My,… we've got sick humor! (Lots of laughter).*
>
> *Brother:* *No, it was when YOU died, we were going to put you in there! (Lots more laughter from all family members)*
>
> *Mother:* *So when we were at the funeral home, and so when the gentleman was trying to force me to buy an urn, I said, "No thanks, I have one." And so we all just started giggling, because we all knew Harry's story about the cookie jar. (Laughter). So, we have his cookie jar here.*
>
> *Aunt Choice:* *Yeah, nice and close.*
>
> *Mother:* *Nice and close, yeah. (Chatter among family members).*
>
> *Grandma:* *It's good to have him at home.*

Figure 10. The 'cookie jar'

Creating Physical Space

At times, family members needed to create a physical separation from other family members in order to be able to gather their thoughts about the loss and to have space to mourn.

> *People who know me know that, when things are really difficult, I need to be alone . . . . (A friend) managed to find a Lodge up-island, on the ocean (for me), that didn't permit children. And it was the type of place where you didn't think. Your meals were prepared; tea-time was prepared. You had no reason to think. You could just be.*
>
> *Like in Australia. I just wanted to sit in bed and. . . . (Sleep all day.) . . . .that's exactly what I wanted to do. . . .But like for me, I don't want anyone else, it's like there's nothing I can do.*

In one family, the family's three sons were involved in the car crash that killed one boy and seriously injured another. While brother recovered in hospital for three months, Father sometimes used his time with Brother in hospital to escape the grief in the family home.

> *I do believe I needed time to be alone and never really had any of that. There was in the hospital, there was always people there, coming to see and there's always be staff at the hospital. . . . (The hospital) was an escape. I never really even thought of it as running away, at the time. But that's basically what it was. We were running away from here.*

Creating Emotional Space

Family members used a number of strategies to find space to process their emotions and thoughts (grieve) and mourn. They were assisted in this process by other family members who maintained the routine work of the family. Often there was reciprocity in families that allowed members to do this work.

> *Some of it was just kinda going around out back, because Hannah loved doing that. . . .just going around out back there, where we walked with her, brought back kind of happy memories. . . .For me, this is a place that I know that I spent a lot of time with her. . . .and it's just nice to kinda get out of the house, as well. . . .But I think more it was just kind of remembering: this is a place that we had fun with her. And I liked that. . . .When I would go around by myself, then there was more just, a lot more thinking, less talking. Just. . . .kinda contemplating what is happening? And allowed me to kinda just be quiet."*

In the following situation, Mother and Father took turns, it seems. Mother was able to function during the day. At some point, however, she could no longer function. At that point, Father took over the work of the home to give her space to grieve and mourn.

> *I'd always get out of bed. I always had a jump-start on the morning. And then he would find me in a corner of a closet, huddled, screaming like an animal. I was scared the neighbors would hear me scream. So I had pillows with me. I'd be screaming because I just, really I couldn't understand how you could hurt that deep. (As Father maintained the home) . . . .as best he could.*

Reciprocity was not limited to marital partners. As the following quote suggests, it occurred between other family members as well.

> *Just to support my sister, my nephew, too, and my brother-in-law. But my sister has always has been so supportive of me; so you try to be there for her all the time.*

Kindness Acts

Bereaved family members gave support to one another in the form of kindness acts in which family served as context to individual grief. These acts were 'work' that family members performed for another in order to be helpful to each other. They were often performed by family members who live outside the household and were the major contribution made by grandparents, aunts, and uncles. Kindness acts occur in abundance in the Smyth family story. It appeared that the primary role of family members who live outside the house was to provide these kindness acts that support the family who live inside the house, giving them an opportunity to maintain energy for their 'work' during bereavement, lending an ear when needed, and giving hope that one day life will seem normal again. As seen in the Baker family story, when there is no 'blood' family close by, the presence of a family of choice can be an important resource for kindness acts. These acts can be very practical help that is given immediately following the loss or on an ongoing basis for many years.

> *"My older sister basically dropped everything in her life and came right over and she lives out of town and she came in every day. (She) brought food and she stayed as long as she could....everyday, all day long for...answered the phone and...for almost two weeks or something like a good week. She was just an absolute rock."*
>
> *"Aunt Choice took care of Brother a great deal...she was just always there for me."*

In some families these acts were abundant, performed by many family members.

> *"The family out here made sure that the crop was harvested, made sure that the cows were looked after. Stuff that we wasn't even in our heads, and all. They did that....just about everybody, I mean because we are a small community, we're related to 50% of the people in the area....I think Uncle and Aunt kinda were more the house-type stuff, looking after the house and the yard and those things.... And my uncles were kinda (in charge)...the first time we came home and picked up messages, I think there was 30 messages on the phone. "*
>
> *"(Brother 2) went home with Uncle and stayed with...his family– I don't think we saw Brother 2 again because...the accident was on a Friday at 1:30 in the afternoon. (And) Tuesday was the first time we saw (him) since....They stayed here at the house."*
>
> *"My Mom and Dad (came from 500 km away and) stayed in the city for a long time with us then....probably (for) 30 or 40 (days) they were here. At our house; in the city, they were in their 70's...They stayed here at the house. They helped with the stuff."*

Family members engaged in kindness acts by providing emotional support through being present and listening, and this was appreciated. For family who lived far away this was sometimes the only thing they felt they could do.

> *Normally because of the time difference I'll give her a call.... I can pick up the phone right now and talk to her about him for an hour.*
>
> *Talk on the phone, more so on the phone. We talked a lot on the phone. We talk.That's, our whole family talks. We phone each other more, more so (now), I find.*

However, at times these family members wondered if their help was useful.

> *Aunt Choice:* *We saw how much pain there was for everybody, and you couldn't take it away. You couldn't help. So that was very, very hard.*
> *Uncle Choice:* *To see what the family was going through, it was painful....It almost sounds like we pushed ourselves on them. We didn't do that....We kinda thought that anything we could do for them, we'd do....They would have done the same for us.*

Not all families were fortunate enough to have kindness acts shown to them. Sometimes this was due to illness within the family but may also have resulted from previously held norms. When families did not engage in kindness acts, some members found the lack of support hurtful.

> *My sister was probably the most helpful. (She is ill) so there wasn't much she could do....We left on our voice mail a message telling people that they could call (her). So she got to talk to a lot of our friends and made that connection. We were able to keep people informed and she passed messages on to us. So that was kind of her. And she talked about Neil, and she brought our mom to the graveside....My mom was ill. She was at the (hospital) for 5 months.*
>
> *My parents are very independent people... they like to do their own things.... I don't think that they realized that they could have been an important part of his life....It seems for others they have this support for the whole year, but I couldn't even get that for a week.*

When families were without blood/legal family members close by, a family of choice provided these kindness acts.

> *Aunt Choice was a person who just, she was like a sister in every way.... I think of all of those hours that (Aunt and Uncle Choice) spent with me and throughout both the time that she(Helen) was sick, the time right after she died and of course right after the divorce in particular.*

The support of kindness and loving acts may lead to a new definition of family.

> *I suppose if anything, it was sort of like it became in the one year Mother and kids were in the condo in particular, we were just sort of more a family than ever...they were just there....More part of our family. So, I think that whole family dynamics differed from Mother and Father and your little family and you moved over into our family and we became kind of an extended family of whoever, it didn't matter, there was just more people in our household....Whether we were in your household or you were in ours, our family is just bigger."*

Sometimes it appeared that family members had the potential to receive the support of many people, family and friends alike, but were so devastated by their grief and had learned in their own families that the way to handle loss was to quietly bear it, putting on a stoic face and keeping silent.

> *In being so separate from blood family, we had others who assumed a quasi-family role. Certainly, P.Y. tried to do that, and took on almost a surrogate father role . . . .as I look back at some of his reactions to me and some of his reactions himself had a real sense of some things and tried to offer help but I just kind of kept going ahead in the same way. We had very good friends throughout this experience who just, people who we had either been close to or just suddenly became close to who offered all sorts of help and assistance to us. And sometimes we could take it and other times I just kind of went on. I think that's a typical male response in terms of you relate to the work and not to the things that should be important in your life and in times of crisis it's very easy to become a workaholic and just kind of get yourself absorbed in what you can do and I certainly fit that to a 'T'.*

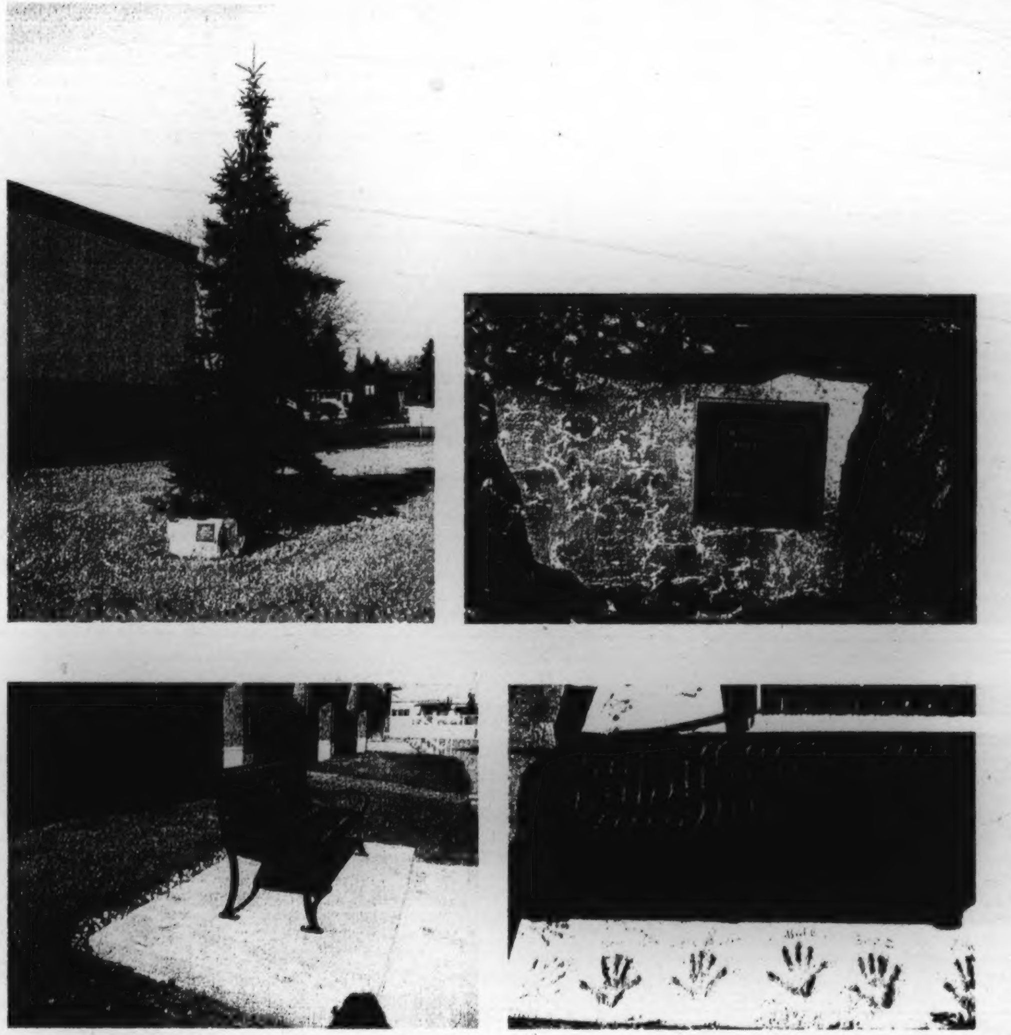
Schools Supporting 'Family Work'

Schools often play a special role in supporting families during bereavement and while this support does not fit the criteria of 'family work', as was seen for Mother Fraser the teachers and students of Neil's school were instrumental in supporting Mother and at least for a short time became her 'family of choice.' They performed many kindness acts that have carried her through the difficult five years since Neil's death. For the Damant family, kindness acts were performed by community members as well. And as Brother 1 suggested, *"people who help you in any way you need and who understand what you're going through are family".* The car crash that killed Ben occurred on Labor Day. The next day, Brother 2 was to start school, but his school supplies had not been arranged. Father Damant stopped on the way home from the hospital, picked up a backpack and school supplies and dropped them and Brother 2 at school the next day. The teacher took over from there.

> *I came home and bought his (Brother 2) . . . .backpack and I just phoned his teacher on the way home and said, "I'm bringing what I'm bringing, if I don't have them labeled, ..." She even looked after those kind of things; labels, pencils and those kind of things, and made sure they were there, because I just put. . . .things in the bag."*

The kindness acts of schools often took the form of assisting families to honor the child, creating permanent memorials of the child.

> *The Elementary School; it's not complete yet, but they're building a room for Ben with his picture and some of his favorite books. And the High School did a Hot Dog Day or a Hat Day. . . .a fund-raiser and donated to (a family charity) . . . .in Ben's memory.*



Figures 11-14. School memorials

In my study, families whose children had died many years ago did not mention the school community extending kindness acts to them. It may be that this is a societal norm that is changing. In fact, the more recent the death, the more complex and personal are the mementos. Note that in the first set of pictures, the school planted a tree and posted a plaque on a rock in memory of the child. This death occurred ten years ago. In the second set of pictures, the school set up a park bench. In the concrete on which the bench sits, are the handprints of the family members and the child's classmates.

Neil attended a bilingual school. His classmates created a scrapbook in his honor. These classmates sang at Neil's funeral and continue to visit Neil's grave on the anniversary of his death. On his birthday, they went to Neil's grave to "visit with him" and invited Mother to accompany them. Mother attributes their attentiveness to their culture, which she sees as less death-denying than is the norm in the dominant Canadian culture.

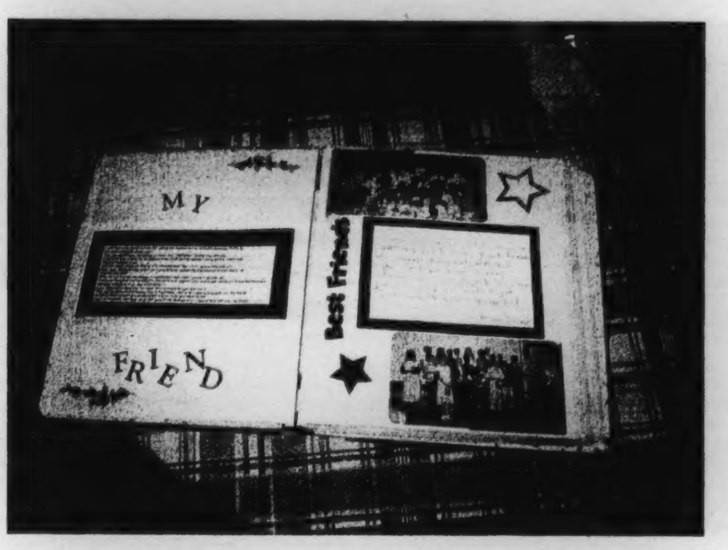


Figure 15. Memory book created by school friends and staff

Loving Acts

Loving acts are what I called those measures of support that one family member gave to another in order to assist him/her during bereavement that required the giver to set aside their own needs in order to be of assistance to another family member. Sometimes these acts tested the strength of the relationship. I distinguished loving acts from kindness acts in that loving acts required an element of sacrifice of the family member's own needs, whereas kindness acts are thoughtful or kind actions which family members offered while still free to meet their own needs. I recognized this distinctive behavior in reviewing the first family transcript but it was later evident in other family interviews and became a theme of family bereavement. While it commonly occurred between spouses, other family members also displayed loving acts.

As Mother Smyth spoke of Father's anger during the first few years of bereavement, I became aware that her willingness to support Father required her to put to her own needs of support from him on hold. Mother believed that this anger was uncharacteristic of Father and was willing to tolerate his anger in order to maintain family relationships.

> *And he would make angry statements towards you, but I knew in my heart not to take it personally . . . .Sometimes they'd hurt, but you knew you couldn't take it and say he really means it towards me, when I knew that he was angry at a lot of things. . . .And I knew; like I mentioned that I'm stubborn. And I thought, "No. You know, I went into this marriage and I know he's going through a rough time. And I'm strong now. And maybe, in the long run, I might not be strong; and he'll be the strong one". . . .He was withdrawing. . . .Now he was going through a really rough time; it was like walking on eggshells here because of the emotion and the feelings. . . .And he's stubborn. But there was no way I was going to lose my family, either.*

Aunt believed that Father's anger was destructive for his family and suggested that he curb it for the sake of his family.

> *He was incredibly angry – huge anger. It just about tore the family apart, more. . . .And so, of course, everyone's been tiptoeing because you don't know what to say or do….I did say to him one time, "Father, if you're not careful, you're going to lose the family you've got left, because you've gotta deal with your anger. . . .You've got to deal with it.'*

In the following situation, Mother had to step away from her own needs in order to recognize those of Father.

> *When Sarah died, he played guitar for her, and I never realized it - that this had a tremendous tremendous impact. As I didn't realize it until the Fall of the year after. We had to buy him a new instrument because he could not play the guitar any more. It was just, he could not even touch it because of Sarah.*

Following the car crash that killed their son, Father Schmidt had to put aside his anger in order to protect his family when he chose not to blame his parents-in-law (who had been caring for Mateo).

> *In that moment when I had that terrible anger at the family (in-law), all of a sudden it was just like (snap) a thought came to my mind. "This is not right. We are going to have to accept this, as this is just Mateo's time to go. This was his life. We're going to have to accept". And, I remember very clearly Mother sat down in a wheelchair out in the hallway. She had gone out in the hallway and sat in the wheelchair and was sobbing there. And I remember bending over her and saying, "Mother I want to make a commitment to you right now that we are NOT going to put this blame on the family because, we're just going to accept and just believe that God is in control and that it was Mateo's time to go. We had no control over that".*

At other times a loving act may create a new strength within the relationship.

> *And then all of sudden I had to have surgery (and my husband took care of me). And it was after that we became closer. . . .You know and I have decided that I*

> *can't seem to find anybody else better than Father. I really do love him. And that Sarah wasn't just the glue that held us together. He always thought that if she died or if something happened that I would leave. And the thing is I loved Father for a long time. And getting to know him, getting this opportunity has made it better for me.*
>
> *And forever and ever, I will carry the picture of him with Ray. Cause Ray, it would take so much. He was so weak, and the cancer, some of the tumors, pressed on his spine. And so he lost a lot of muscle function. And, to just to go to the bathroom, when he could still walk, Stepfather would get him sitting up on the edge and then Ray would put his arms around Stepfather's neck and he'd just rest his head. And he'd close his eyes. And I can just, and Stepfather had his arms around Ray. . . . (After Ray died) Stepfather tried to commit suicide. . . .I was angry. . . . (because I hold this image) I've forgiven him.*

Sometimes surviving siblings performed loving acts on behalf of their parents.

> *I think Dad and Mother (step) would be pretty disappointed if I said that. . . .I didn't want to go to the cemetery. (So I go but I don't need to).*
>
> *And Sister actually just brought his ashes home. I couldn't go to the funeral home . . . .I wasn't able to bring his ashes home. It just was too painful. But then, in the last month or so, well, a little more than that I said, "I'm ready to bring his ashes home now". . . .Sister said, "Mom, could we bring him home? I don't want him to be with strangers any more". And I said, "I feel the same way". And so, she did. She went back there. I heard this knock on my door; and there's a very tearful girl clutching her brother's urn in her arms.*
>
> *(Mother) doesn't need any more on her plate. And Brother just can't seem to, to give her some, some slack . . . .So I get very frustrated with him . . . . (So) now I am the peacemaker.*

It appeared that in many families loving acts seem to lie within the role of grandparent, wherein they were called on to remain strong even though at times it may have been difficult for them to be present in order to provide support to her family. Grandmother explained how this was done.

> *Grandmother: But I find that if you just sort of behave your way through a situation, you know (it helps).*

Although I was unable to interview grandfathers, other family members told of the loving acts that they had performed.

> *Grandfather internalizes his grief more than I do. (But once he said) "Just because you don't see me cry, doesn't mean that I am not grieving.' . . . .He picked up a rock (family tradition) and he put it by Ray's picture, which (he) would never have done before . . . .he's gentler.*

In the following scenario, Grandfather spoke at the grandson's memorial despite his own grief.

> *And Grandfather spoke . . . .So he said, he shouldn't be doing this because it's his grandson. He was supposed to go before his grandson.*

Family members provided support to each other in a variety of ways. Together with creating space for individual grief loving acts and kindness acts formed the context for individual grief, providing a safe 'nest' of support. When family allowed individual members to do their work during bereavement in a supportive context and work together as a social group, they were able to restructure the family, finding a place for the child in their ongoing lives.

Restructuring Family

In responding to the death of the child, family members recognized that the death of the child had necessitated the creation of new roles and routines that allowed them to carry forward through their ongoing years. Routines and roles were described and evidence was uncovered of the work families did to readjust their routines and fill the roles left vacant by the child who has died. But while roles were changed through this work, a place was maintained within the family for the child. Not all families in this study had been bereaved for a long enough time for there to be evidence of restructuring. Although it has only been two years since Hannah died, it appeared that the deJong family had readjusted family roles and routines and found a ongoing place for Hannah in their lives. The Schmidt and Broders families demonstrated evidence of restructuring family. While the Baker and Stewart families had been bereaved for many years, their families had not restructured as a family unit but instead had undergone divorce wherein two new family units had been created.

Recognizing the Role(s) Played by the Deceased Child

Roles initially were left empty following the child's death.

> *That was what was really excellent, we were pretty much opposites. We were like, totally different. (We would argue.) Arguing isn't the right word. It's debate. He always wanted to do things. He was always active and everything. He was, Mom and Dad won't, will deny it, but…he was very smart. He was very sharp. I looked up to him.*
>
> *He'd be doing something and he'd be daydreaming. He'd be in the corrals and he'd be daydreaming. And I'd give him heck for (not) pay(ing) attention to what's going on around you. A cow could run into you while you're daydreaming….Ben was a kind, giving, gentle, loving, loving little soul. He'd bend over backwards for anybody. Ben cared for others more than he cared for himself…. And Mother and*

> *I would be out there and Ben and Brother 2 would be at home. And Ben was - he loved to cook…so he made lunches or he made suppers.*
>
> *If people say what brothers are like, protecting you or whatever….And when I see them (friends and their older sibling) together and doing stuff together, that's when it hurts more….It's like, that was what I was supposed to have….That's when…you miss him. It's kinda like, 'I should have had that.'*
>
> *One night I was just thinking about him and wanting to have him back, just a need for something….lots of people say, a part of me was missing. But I don't know if it was that or something else. It was just, I needed something….There are these people at Church who have a brother 2 or 1year younger than Mateo would have been right now and I don't know, it's, it's like seeing what I would have been like. What my family would have been like…. So I heard people talking about things that happened in the past and how Mateo died and…then one day, it was just Mateo, like Mateo died and I get what they're saying now.*

Role changes were particularly apparent for siblings/peers who felt they needed to take on some roles previously held by the child who has died.

> *Mother: And he'd bring friends from all different groups of kids together….and if kids were maybe having…little fights or little tiffs or hurt feelings and that. And Ray would always work it out so everybody was happy again.*
> *Sister: I'm starting to think I'm the peacekeeper (now).*
>
> *She was great; because she was that person out there leading them, guiding them, coming up with all of these creative ideas. . . .Helen was there as the first born of that group of very creative children to start that ball. . . . (having) that organizational role.*

In the previous quote, one of Helen's cousins (firstborn within his family of origin) assumed the role of leader for the surviving brother and cousins. Sometimes siblings were aware of the role left vacant in their family by the death of their brother/sister very quickly after their sibling's death.

> *I got up and then my parents told me Mateo had died last night. And, you know, I don't even know how I really felt. But I remember the strangest things, like. . . . (recognizing) I had to become the older sister right away, have that role. I don't know if that will ever change, but you're oldest and you're like role model for your younger sister.*

Parents too adjusted their roles as mentors often based on the ongoing relationships within the family.

> *One of the hardest things for me, probably, that I had to deal (with) . . . .he was my firstborn. He was also my son, that I was so proud of, and had so many dreams. . . .just of working with him and of teaching him and of seeing him, whatever he did for his life, seeing that. . . .Seeing that come to pass and happen. And. . . .it's different with daughters. . . .and it's not like I don't wish the*

> *same and want the same for the girls, it's just a whole different aspect. They're not going to be, probably, going out there, pounding nails and, doing heavy labor. . . .And don't get as excited about football or about. . . .it's different.*
>
> *I miss that part, kind of the noise of kids. Because Hannah was. . . .a truck kid and Sister is. . . .she's a girl,(she) can be noisy at times. But, by nature, she's a quieter kid. (So) some of the stuff is different. She won't; she doesn't really enjoy watching hockey with me. Sister's not gonna be a. . . .be a hockey person either. Hannah, well she's was, she was kind of a tougher kid. . . .I often think, 'What would it be like now if she was still here?' . . .And then I really think, 'It would be a lot of fun. . . .With both girls, right now, and they would just; they got along well and they would just love being outside. You notice, especially the Spring here, that Hannah isn't outside yet. . . .And Sister is becoming more that way now, even without Hannah I think if they were both out here, they'd be tromping through the woods together (laughs) and doing all this stuff.*

While the role of active parent changed, the role as mother and father continues.

> *He's my firstborn. . . .When you have a kid on your hip for all those months. And I think, at first, they think they're an extension; you're an extension of them. . . .He's my child. . . .so he's still my kid. . . .I mean he's not here with me, but he's still my son. . . .He's part of you. I mean, shoot, he's the one that taught me how to be a Mom because he was my first. . . .And the whole 9 months of carrying him and the whole thing, I mean they become part of you. It's always there.*

But nowhere was there seen as big a shift in family roles as that experienced by the parents who lost an only child. Both of the children in the following quotes were ill for their entire lives and required constant, intense care. Their deaths left major holes in the lives of the parents who had been their lifelong caregivers.

> *For 7 years I took care of my son. . . .And he needed us for everything. And . . . .that becomes . . . .a big part of your identity. . . .the main thing is: 'what do you do now? Who are you now?' . . . .Patrick was my only child. So you struggle with: am I still a mom? And those kinds of things, and just really figuring out who you are without him. . . .that's not easy, and . . . .it's hard. . . .And you have to redefine yourself as a couple, too.*
>
> *I was her mom! Sarah had changed our future, like it was going to be so different anyways but a child does bring a lot of hopes and dreams to your future, that you just don't realize how important they are.*

Surviving children revealed the role they took on as protector to their parents.

> *I think that really kind of made me grow up because I was the younger one. . . .it does definitely make me more mature, going through something like that, because you have to go through it without crying the whole time. . . .your mom's grieving too. Your parents are grieving too. So you have to, you can't. . . .It's not like it's just you. . . .I think I tried my best (to protect them).*

This seemed to occur even when surviving children were too young to be consciously aware of this role shift.

> *She (aged three) would come over and she'd hug me and whatever. And I remember one time that she came and crawled; I was laying on the couch and she came and crawled on top of me and just started crying with me.*

In the following situation, the Sister (aged three and a half) somehow learned to bring Katrina's picture to her mother in an effort to comfort her.

> *One night she gave it to me and I said, "I don't want this picture. I just want her to hug me". And she said, "Well, I'm here. Hug me". (laughter) And I got all my parenting classes with my youngest daughter. (laughter) And I thought, "Yeah. No kidding. How does this kid feel? All I want to do is cry". So, every time I cried, she hugged me, instead of bringing the picture . . . .After that, she never had to bring me the picture again.*

Changed Routines

Routines changed for family members individually and as a group following the death of a child. One of the mothers who had spent her child's entire life caregiving, now had time to pursue her own interests.

> *I went back to school and I had gotten the art studio before but it was very restricted. I could only be there for a very short time but I go there more often (now)."*

In this same family, the surviving brothers had fewer chores

> *I don't really help out as much anymore . . . . there's not as much responsibility for us to help out."*

In other families, the chores will need to be redistributed. The families in this situation recognized the need for change, but had not yet had time to make the changes.

> *We had quite a little system going. Brother 1 was big enough to rake the hay and he would come out to the fields. . . .or harrowing, helping out with field work. And Mother and I would be out there and Ben and Brother 2 would be at home. . . .And he and Brother 2 looked after keeping the house in a semi state of array.*

For some families, these changed routines had the potential to change family connectedness.

> *We don't sit at the kitchen table. We all fill our plates and go into the living room and watch the news or watch T.V. or sit together in the living room. It's very rare we'll sit at the kitchen table, like we used to, as a family. . . .And talked about the days and how school was and what we did and. . . .Now it's the norm not to be at the table.*

A Place for the Child

The families in this study made it clear that a place for the child required time to secure. While, as previously demonstrated above, family worked to create this place through family mourning (telling stories, observing rituals and meaning making), in my study it was only in the families who had grieved and mourned for some time that this place of the child was evident. However, many families sensed early on that they will need a place where the child continues to be part of the family. Even in their first year of grief families had a sense of the child's presence and the need to create a place for him or her. Family members' talk about the ongoing presence of the child sometimes confused others who understood them to be talking about someone who is still alive.

> *They (cousins) talk about him like he's still part of the unit.*
>
> *He's in my head . . . .And just because he died doesn't mean we don't talk and think about him . . . ..He's a reality in my life. I know he's not physically here, but he is here . . . .it's almost like we all have family members that are gone to live thousands of miles away. We don't talk to them every day . . . .but they're still there. They're still family . . . .He's just . . . .he was the most important thing in my life . . . .And he still is . . . .he still occupies so much of my psyche. I mean he's; I don't have to do anything for that relationship now . . . .But he is still; but he is still there. I think, because he was a habit, or I was so used to him in my life."*

After 10 years, Mother Schmidt speaks of Mateo as if he were on earth sometimes confusing others who do not know of his death.

> *But he's still your kid. And that's why I still talk about him and I think – actually one of my neighbors, I was talking about Mateo. And she knew my two girls because my two girls went to school with (her kids). So she says, "So, by the way, where is this son of yours that I always hear you talking about?" And I said, "Oh, he died a few years ago." She goes, "Oh!" He's in my head. And just because he died doesn't mean we don't talk and think about him.*

Further, Mother Schmidt was able to explain the difference between caring for her girls and Mateo's place in their family.

> *He's a reality in my life. I mean . . . .I don't have to do anything for that relationship now. But he is still; but he is still there . . . .he has no needs. You're always thinking about your kids' needs. So I don't have to worry about his needs. But I still think of him. Just like if my girls go to camp. I don't worry about their needs during that week. I still think about them….I mean he's not here with me, but he's still my son….You just don't say stop talking about him, stop thinking about him.*

Mother Broders described how the family created Katrina's place this way.

> *Father and I decided that, they wouldn't grow up in the shadow of Katrina's death, that we just had to get it together and move forward. It wasn't going to be a sad place at all . . . . (But for a time) we were all messed up because we were 4 instead of 5 . . . .We just decided to do things that made her part of it, without making her everything.... So, we'd buy 6 pink roses, when anything was going on, we'd always have 6 pink roses, 6 because she was 6 years old. And amazingly, one would never fully open, it was like she was telling us . . . .But she didn't make it to her full 6th year . . . .So we'd make it all the way through 16 and she's telling us: just accept it.*

Today Katrina has a place that is acknowledged around the time of her birthday but it is no longer Mother who orchestrates the celebration. It is her sisters who need this and Mother has given them the responsibility for finding ways that fit for them and their families. They now organize family events to honor Katrina's presence.

> *(After about 10 years), 10 was enough for me.... it's funny how I didn't have that need any more. And when they said, 'What are we doing for her?' And I'd say, 'I don't have a clue ....it's your sister. You plan something.'...(So now) if there's a good concert coming to town, we go as a family. The way...we looked at it as it was her forcing us to quality family time because any time you asked her what she wanted to do it was, 'Let's do a family day.' So we did that as our cue, as our reminder. And on her birthday, we decided we would (have) a family day....We decided, wherever we are, we'd have a nice dinner together. Now Sister 1 wasn't with us this year and her and her husband were out for a nice dinner. And I said, 'Just (do) something you can do with your kids down the road, if you feel that you need to do something.'"*

When families are able to work together both as a group and by providing support for the grief and mourning of individual family members, the family was able to restructure and learned a way to incorporate their child into their ongoing family. But not all families were able to do this.

When There Is No 'Family Work'

In my study, not all families were able to work together as a group. No shared family work was seen in the four divorced families in my study. As well, the Barnes, Fraser, and Stewart families showed little or no evidence of a supportive context for their individual grief and mourning within their family. For Mother Baker is supportive context was provided through her family of choice. When no family work occurred, family members had to find ways to travel through the processes of grief and mourning alone or find others outside the family to assist them in their bereavement as demonstrated by the role that school's staff and friends played in the bereavement of Mother Fraser.

When family members had not worked together to create the child's place, the place was held within individual family members.

> *It has gotten to be this very private place for me that Helen is part of, just this private place. It's not that I won't talk about her. (Each year I go to the cemetery on her birthday), But I found that the year when (2nd husband) went it just interfered…(and) after that, I didn't do that. One year Brother went with me. The first few years he didn't even know I went and then I told him and he said he wanted to go and he did come that year and that was okay. If he was there it was okay and I think one year maybe both Brother and Sister came with me, but again, it's odd that Sister isn't part of that. It is kind of like Helen is part of that family that was me, Father and Brother and she's not part of anybody else and so as a result. . . .nobody else can be there during that time. I don't know what it will be like if Father came. I certainly have never felt free enough to ask him to do that. I tend to think that he probably wouldn't do that. It would be interesting to see after he hears this whether he decides we should try to go together or whether I decide to ask him. I don't know, but I know I don't think so. I think it's a private time that I need to acknowledge her."*

For some individuals, it can take considerable time to find the child's place. Baby Lawrence died thirty years ago, and it is only within the past five years, that Father Stewart has begun the process of grieving, mourning and finding a place for his child who died.

> *When I would drink, I wouldn't feel anything . . . .I think I cried in the basement, by myself. And (now) I feel that mourning. I've cried more in the last 5 years than I cried in my whole life before that . . . .Not understanding it at the time. But today I see it . . . .I don't hear my children talk about baby Lawrence.*

In my study, when there was no sharing of family stories, it appeared that individuals had to struggle alone to understand the many feelings and thoughts of individual grief.

> *And I was just so raw…just so much full of pain and hurt…. I never had a chance to grieve. It just seemed like the world should stop, with how much pain we got…. I was shaking….I promised on his graveside I'd never drink again…I couldn't keep that promise. Couldn't do it for 30 days. That's always been troubling my mind.*
>
> *You have all these people around, and yet you feel so alone inside.*

Without the support of family, participants found it difficult to create the 'spirit of the child' and to make meaning in the child's life and death. This may have created an atmosphere where the bereaved family member struggled to accept their need to mourn. They appeared stuck in a place where all they could do was to hold their feelings inside.

> *There were times when I didn't cry at all. I don't remember crying at the funeral. I don't remember feeling anything . . . . (but) they (feelings) changed. Probably this*

> *year, for whatever reason, I've been able to cry more. I've been able to, I guess, feel the loss, I just felt the loss this year (five years after the death.*

> *I never cried. . . .She might have. Actually, she did. . . . (But) holding her and comforting her, I can't remember doing that. . . .But I, you know I think I cried in the basement, by myself. . . .You try and hold all the eggs together…you don't show it….You don't ask for help. . . . (You hold it in) . . . .All the time. . . .When you have no support, you don't understand it.*

For some participants, their inability to mourn openly and their inability to give and seek support may be due to their previously held beliefs and attitudes,

> *Just very, very negative stereo typical type things of saying, "I have to be strong for my family. I have to stand here and take this absolute brutal battering that I am going through and I can't cry and I can't show emotion….Keep soldiering on and that's the way that you're a good man".*

or previously held patterns of coping that may take many years to overcome,

> *I'd known for a long time…that I was probably an alcoholic and how alcohol got me in trouble. I'd already had many blackouts. I'd already had problems….I know it caused me problems with relationships. It caused me problems with the family, with police, with my employers. I tried to control it all through that (the bereavement) . . . .I've been sober for 22 years . . . .You get messages in your life in strange ways.*

or norms set in the family before the death occurred.

> *They're (Father and Brother) not comfortable at all, talking about it . . . . (Brother) doesn't talk about Neil . . . .I can talk about him and he'll give me a hug and . . . .And stuff, and be very sympathetic. But, no, he won't talk about him.*

Mother Fraser adds:

> *And Father's family, they just have very different ways of dealing with grief and loss that I find odd....In fact I think when they phoned, was it on his birthday or the anniversary, but Grandma wouldn't say what day it was….I mean I always reminded her it was his birthday….She just let it pass.*

Some participants suggested that they needed to create a family of choice in order to allow themselves to mourn. In the following example, Neil's mother talks of the kindness of his friends and brought her a sense of support.

> *And then at a year, a year anniversary, I got a call from one of Neil's friends, who said, "A bunch of us are going down to the cemetery to visit with Neil. Do you want to join us?" I mean I didn't know quite what to do. That year was very difficult. There was about, I don't know, 10 of them or whatever. And then they did that the next year….I had a visitation from two of the girls. A visitation to see me: on the anniversary. And they asked me to get out the book. And they talked about Neil and talked about how they remembered him. And one of the girls was so cute. She said, "Now, Neil had this really cute pencil case", she said. "Do you still have it?" I said, "Yes". "Well, could I see it?" I thought, "Oh, my gosh, where*

> *is it? We've moved. Do I know where it is?"...And I found it. And I gave it to her. I thought that was so sweet... She remembered a pencil case.*

But, sometimes family members turned to people outside the family to tell their story. One participant reported telling the story to a woman with whom he had an affair which ended the marriage.

> *As a matter of fact one of the first times I really told the story was when I had the affair. And again it came out of me, it just kind of 'Oh'. And was listened to, this was just utterly bizarre, silly thing. But I told the story and then I came much more comfortable in terms of telling the story to others.*

In my study, families who did not remain together showed no evidence of family work. In contrast, all families who stayed together did engage in family work. Most often the divorce was attributed to problems that already existed in the marriage. However, it may be that for families who are not able to work together, the personal attitudes, beliefs and patterns of coping did not allow the creation of family norms that would facilitate joint work.

> *It (Neil's death) didn't cause it. You go on and stay married to protect the children. And you wonder if it is. And then this happens and you question things. I mean, it was hard for me to decide, but if that's what would work best for me and for the family....This family...I have no regrets about that decision. Not about that.*
>
> *Father:* *I ran away from that which I couldn't cope with anymore. And that was you and me trying to change and grow together, and trying to put life back together again or to get a new life together. And...I snapped. And just went off my merry way. And it's one of those things. I don't think we would've made it anyhow; we should've tried. I just don't think the communication stuff was there to do it. We could have, maybe. But it should have never ended the way it did. And that was sheer stupidity on my part.*
>
> *Mother:* *When we told our friends that we were divorcing, they were shocked. On the outside we looked like we were this happy couple."*

Father Stewart reported his perception that he had a strong marriage. However, he reported that his individual pattern of coping (using alcohol) did not allow his marriage to survive. When he began drinking, he avoided grieving and avoided the needs of his family during bereavement. Father Stewart was the only member of his family being interviewed and his family members' perceptions may differ from his.

> *Ah, it was exciting. We were partners . . . .You know we did things together. We took holidays together . . . .We took holidays with the family . . . .We were complementary . . . .Our communication was fairly, really good . . . .very trusting. It was open . . . .I maybe put her on a pedestal. But today I see that differently . . . .Where we did things that allowed me to screw up later on . . . . (Before Baby*

> *Lawrence died) . . . .I renovated the basement and put a sewing room in there and thought she'd like it. And that allowed me to be at (meetings), consciously or unconsciously . . . .I think it was these, or results of self-centeredness, that takes you . . . .for more and more and more . . . .Not understanding it at the time. But today I see it . . . .But (at the time) she wouldn't have said that . . . .She would have said, "He did these things because, because I wanted it and he was willing to give me what I wanted" . . . .I did it willingly.*

Even when families are not able to do their work together during bereavement, individual family members were able to come to terms with their loss and find a place for the deceased child.

> *Certainly for me just in terms of making a decision once I finally got a hold of what was going on, that I could either spend the rest of my life wallowing in grief and in denial and anything else that I wanted to, or I could just get my act together and kind of get in touch with some of the feelings get in touch with the story of her death, with the story of her life and use it as a positive force in my own life. And I think that has been of one of the ways of making a terribly tragic situation something that I have been able to live with and grow from and put back together. (But) I wish I had talked to (Mother). I wish I could have consoled her more. I wish I could have allowed myself to be consoled, but we were not there yet and I certainly wasn't . . . .I think we were just two nice people who . . . .didn't see things in the same way . . . .And it just didn't work.*
>
> *And I made two calls and I cried. I called my mother. I called my good friend. And I went to work. I let her take everything that she wanted. I said, 'When you're ready to go, just go.' And the first of May she was gone….In the middle of June I went to, to my boss and I said, 'I've got a drinking problem. My wife is gone. I've gone through the bankruptcy. I don't know what to do.' We walked down to AADAC together….(Later) I asked her if she wanted to try again. She said, 'No. I'm not falling for it.'…There's always a breaking point for everybody….I used to think she was weak in some ways. But now I know she has great strength….She did the right thing and I'm grateful that she did….(At the beginning we were given)A poster…I still have it. It's a waterfall in the forest (and says) "love's meaning is life's secret" . . . .I asked him (the man who gave them the poster), 'What does that mean?' He said, 'Well, it's a journey. In the journey, you'll find out.'...It pissed me off. Just, you know, give me the short answer….(now) I understand."*

Moving Forward/Seeing Progress

Participants in this study reported that although the experience of losing a child was devastating, they believed that they had learned from the experience, they could see their own progress and they could see a benefit.

> *We got the CD's and we played them. And we cried. But it's getting better. You know, it's easier.*
>
> *And I didn't really experience a lot of anger after that until one day we were heading down to a friend's place. And we realized we were going to their place*

> *for the first time without Mateo. (Mother: He had a hissy fit.) And directing it (outward). Yeah, everybody heard me. . . .it was actually a really healing thing.*
>
> *There's a positive somehow. I don't know how, there's this . . . .strength, growth, there's something . . . .that it gives you . . . .It also makes a lot of things not important that once were important. Part of me just has to grab it . . . .That peace will be worth achieving.*

Some participants reported that the benefits were personal, but also extended to others with whom they shared their experiences.

> *That's…so healing for me; when I can share with a group of people about Hannah's life. And when I talk to them after it actually touches them somehow, I think, "Okay. You know there's something good coming out of this".*

One participant was surprised to find that not all family members learned the same lessons from the experience of losing a child.

> *I just assumed they (various family members) all got the same message. The first time you find out that they didn't, that they're just really the people they were before, well, you're like, 'Well, what's that all about? (laughter) I think differently now. She was my daughter. She was your niece, whatever, don't you?' That's a wake-up call, too, that you learn differently.*

Lessons could be learned many years after the death, even during the interview itself. Father Stewart used the interview to think about his own experiences and recalled the contrast between how his uncle and Baby Lawrence are remembered.

> *And when you're talking about family there….In my mother's family, on their tree, there's Uncle, Uncle M. and then my mom. And Uncle M. died at about 8 months. He was very asthmatic. But they always talk about Uncle M….Families carry their grief along….And my mother and Uncle always talk about Uncle M….into their 80's….But I don't hear my children talk about Baby Lawrence….But there was Uncle M. There on my tree. There's Uncle M.*

He also became aware that in his own family, loving acts had stopped when the baby died.

> *I think this is the most important part….If you're not doing the loving acts, you don't feel it and you're not getting it….And it's gotta be unconditional….And that's the only way you can feel it; and that's the only way I can get over it….It takes great courage. And then, the two people that are going through the grief in the family, or the children too….You don't know, but if you're not, if you're not giving loving acts and feelings, and sometimes, if you're not giving it back, you're not even feeling the loving acts that your spouse is giving you.*

Brother Smyth reported that sharing his thoughts in his individual and the family interviews made him reconsider how he was living his life since Harry had died. He decided to make a change, leaving home and his previous need to protect his parents.

Mother Smyth also commented on this change in her second interview, supporting her son's decision to move out of the house and recognizing how her family continues to grow and learn from their experiences.

> *The last time we talked I didn't realize how and to what extent my life was been put on 'hold' it was a big eye opener for me….April rolled around and I had a choice to make….The next thing you know I'm driving out to (another province) with my car packed to the roof with most of my belongings. With regards to the separating from my family, I didn't think of it as running away. More of a fresh start that I can control what happens in my life. Still to this day my mother asks and is waiting for my return home, to her disappointment I will not be returning home any time soon. This move has been the best thing for me. I had to leave the comfort zone. A part of my thinking was I had to fix myself before I could continue on with my life but the thing is I didn't realize is, that to help myself I needed to get on with my life. So the days spent in bed, till 4pm just crawling out so my parents didn't realize that I have been sleeping the whole day. The sleep was a mixture of mental exhaustion, probably depression. The odd night I would have a dream and Harry would be in it… (he) was never sick. Thinking back to my memories for the past six years most of the memories have been when Harry was sick. (Before) I was still in the state of mind where I had to protect my family but (not) realizing in doing so I was setting myself up for a long road of tears, anxiety attacks overall depression….Living (on my own) gives me a sense of purpose, for the first time in a while I feel like I'm moving on. I recently flew back home to see how much has changed, and I was satisfied that there was a significant change; it feels like that I'm the one moving on. Although I will never get over the passing of my brother but that doesn't mean that I can't have a life.*

While the death of a child brought many changes for the individual and family, families can work together to support one another and create an ongoing place for the child and their family. Family norms, beliefs, routines, and roles before the death can guide them in their process of grief and mourning, allowing them to create family anew, learning that "*We're still…family…(and even though) Something has changed, there's still a lot that (is) the same….(and) They're stronger than they think.*" Finally, the pain of grief does seem to dissipate over time if the family has done is work. As Mother Broders so aptly suggests, *"(the child is) forever a part of you (and grief becomes) just a journey that you carry (so that family is once again just about) true love"*.

CHAPTER 7
DISCUSSION

The purpose of this study was to describe and understand the experiences of families during bereavement following the death of a child. This study focused on two units of analysis, the family and individual family members. I was interested in how families, as discrete units, grieved, mourned, and adjusted to the death of a child, as well as how family members influenced and are influenced by one another. This approach, that of examining families as well as family members, is unique to the area of bereavement research. Despite a substantial and growing body of knowledge around bereavement, researchers have tended to focus on individual bereaved family members. This has been particularly true in studies of grief and mourning following the death of a child, where the individual experiences of parents and in a few instances, of siblings and grandparents have been reported. As a result, the important work some families engage in collectively to grieve, mourn and restructure their family, findings from this study, have not been previously identified.

The findings of the current study suggest that there is no single trajectory through which all families experience bereavement; but there are commonalities that occur for those families whose members actively and collaboratively work together during this time. These commonalities were absent in the families who were unable to work together. I identified a component of family grief (quieting) and family mourning (creating the spirit of the child) that led some families to family restructuring, wherein the family established new routines and roles and found an ongoing place for the deceased child within their new family structure. To accomplish this, these families had to work together as a social group. The conceptualization of quieting as an important component of family grief is unreported in the literature. This quieting appears to foster family members coming together to prepare for their shared work, a type of "circling the wagons."

It is important to note that not all families were able to work together as a family group. Of the families who were unable to work together as a family unit, some families engaged only in individual work. In other families, individual bereaved family members were able to elicit support from each other (through creating space, kindness acts and loving acts). In this way, family provided individuals with a context of support. I refer to this phenomenon as “family as context”. In families who were unable to work together (whether that work was individual or done with family as context), individual family members were left to create their own private place for the child. With no family work, the child dwelled only within the individual's memory and experience and not within the family. This is a significant contrast with the finding that when family work was engaged in by families, these families maintained an ongoing place for their children. Further, families engaging in family work realized a new-found resilience and awareness that contributed to the group and growing stronger as a family.

There are four key areas of findings that I will discuss in this chapter. First, I will discuss the parallel processes of work both individual family members and family units engaged in during bereavement. These parallel processes include the ***individual*** process of grief, mourning, and reformulating self; the ***shared*** process of families including family grief, family mourning, and restructuring family; and the process of family as ***context*** of support for individual family members. Significantly, these parallel and interconnecting processes have not been reported in the literature on bereavement. Secondly, I will discuss the components that make up the shared family process experienced during bereavement, including the unique finding of a component of family grief that I have conceptualized in this study as '*quieting*.' This shared family process wherein family members isolate themselves somewhat from their external world as they work together toward restructuring their family has never before been described so comprehensively in the literature. Third, I will discuss the additional aspect of the family process engaged in by families during bereavement when the family functions as context for supporting individual family members during bereavement. This finding differentiates among the three ways family members support one another during bereavement. Lastly, I will discuss how the family process is related to 'family work', an under researched concept. This latter finding significantly extends the current understanding of family work.

Studying families as discrete units presents many challenges and when the subject is emotionally painful, as is the case of investigating bereavement, the researcher is faced with unique challenges when trying to recruit and interview participants. I will discuss the methodological implications of these challenges and my experiences related to this while conducting my study. I will close the chapter with a discussion of the limitations of the study and implications for research and practice, including as well, personal reflections about the process of conducting this study.

The Parallel Processes of Individuals and Families during Bereavement

The findings of my study revealed parallel processes engaged in by individual family members (individual) and the family unit (family) during bereavement composed of grief and mourning, which led to coping in the form of family restructuring and individual self-reformulating. While the individual bereavement process has been well-documented in the literature (Davies, 1999; Ponzetti, 1992; Rando, 1986; Rosenblatt; 2000; Stroebe & Schut, 1999; Stroebe et al., 2001), I will briefly review it in order to highlight the correspondence between individual and family processes.

During the individual process, family members in the current study reported a variety of feelings, most notably those of sorrow and guilt, and thoughts, especially those that aided in finding meaning in their experiences. These feelings and thoughts have been reported in the literature and are commonly referred to as symptoms of the internal process of grief (Archer, 1999; Balk, 1990; Davies et al., 1998; Parkes, 1975; Ponzetti, 1992; Rando, 1986; Rosenblatt; 2000; Rubin et al., 2000; Stroebe et al., 2001).

Family member participants also reported a set of behaviors, commonly referred in the literature as mourning (Archer, 1999; Parkes, 1975). These behaviors fell into two categories, those that could be termed enduring and those considered suffering; terms initially described by Morse and Carter (1995). Behaviors of enduring were demonstrated when family members strove to carry on their routine activities of life, such as providing for the care of their surviving children, going to school, and maintaining employment. Grandparents in this study reported that they felt the need to "remain strong" in order to support their children and grandchildren, a finding previously reported by Ponzetti (1992), which I considered as a component of enduring. Behaviors of suffering were evident when family members reported episodes of uncontrolled weeping, outbursts of anger, and the need to be alone. The conceptualization of enduring and suffering parallel those of restoration-oriented behaviors (enduring) and loss-oriented behaviors (suffering).developed by Stroebe and Schut (1999) in their Dual Process Model of Bereavement.

Further, family members in this study reported "triggers" that would move them from enduring to suffering and back again to enduring. While Stroebe and Schut (1999) discussed the movement between restoration-oriented behaviors (enduring) and loss-oriented behaviors (suffering), referring to it as oscillation, they did not identify the events that led to this oscillation. The identification of exact triggers has not been heretofore reported in the literature, even in the seminal work by Morse and colleagues. The triggers for enduring found in this study were often as simple as the presence of the surviving children, the demands of participants' workplace, or the need to maintain household chores such as cooking and laundry. Triggers for suffering that were reported by participants were seeing the deceased child's possessions, walking past the child's room, and seeing the child's friends. At times, family members deliberately used triggers, such as watching family videos in order to allow themselves to enter into suffering.

In the current study, many family members reported that while the emotional pain of bereavement was difficult, they came to recognize that through this pain they experienced growth and as a result had come to value their suffering. As well, individual participants reset priorities, having learned to value supportive relationships, and several reported that they had given up on relationships that were non supportive. These relationships extended into their marriages when spouses made the decision that their relationships were unfulfilling and their marriage impossible to maintain. In these instances, spouses made the decision to divorce. Participants also reported the need to "give back" to others, and did so through fund-raising activities in remembrance of their children, public speaking about their experiences, and leading support groups. These aspects of self-reformulating parallel those reported by Mayan et al., (2006). However, unlike the work of Mayan and colleagues (2006) about reformulating the self during enduring and suffering while experiencing a life threatening illness where the process of self reformulation began only when enduring and suffering had ended, participants in the current study reported that self-reformulating was part of the process where they moved back and forth between enduring, suffering, and self-reformulating and not the outcome of enduring and suffering.

While family members were experiencing this process as individuals during bereavement, families experienced a parallel process as a group. As in the individual process, families experienced grief and mourning that led to a further element of the shared family process that I have termed restructuring. While elements of this process have been previously reported in the literature (Klass,1996; Rando, 1986; Rosenblatt, 2000; Talbot, 2002), the comprehensive process has not. The elements of this process will be discussed in the following three sections. However, prior to doing so, a further finding of note regarding the relationships between family members and the deceased child bears mentioning.

In this study, I was aware of the difference in experiences reported by family members who lived inside the family house and those who resided outside. Initially it appeared that how family members shared in the family process that contributed to restructuring varied depending on where they resided. However, after careful review of the data and further analysis, I determined that it was not family member residency that influenced their contributions to the family process during bereavement, but rather the nature of the relationship between the family member and the deceased child. After all, family member residency tends to be determined by the relationships among family members, i.e. parents and siblings of the child most often live together whereas grandparents, aunts, uncles most often live separately from them (there are exceptions, of course). Further, family members who lived in the household had shared routines with the child and hence after the death were confronted with disrupted routines of the household. For those family members who lived outside the household, daily routines were less likely to be disrupted. Hence, they had a choice as to their involvement in the family process. Participants in this study reported greater participation in the shared family process when they resided in the household than those participants residing outside. As well, it was participants in the household, particularly parents, who reported the greatest need for support while family members who were still close to the deceased child, but who lived in a separate household reported giving support to the family as their greatest contribution to the family process during bereavement. This process of support will be further described in this section on family has context during bereavement.

The Shared Family Process during Bereavement

In the current study, nine families reported a family process that defined their functioning as a social group during bereavement. Yuen's definition of family used in this study (see page 4 Chapter 1) expands on Burgess' (1926) classic definition of family as "a unity of inter-acting personalities." It was this succinct definition, which underlies the thinking of family as a social group, that unfolded as I listened to the first few families tell their stories of loss. These families told how members took on various roles and carried out tasks that allowed them to establish and maintain functioning together as a group toward common goals. Corey and Corey (2006) suggest that goals of a group are often different from the goals of individual group members. The family stories of these nine families demonstrate the individual's need to grieve, mourn, and reformulate themselves together with the need of families to grieve, mourn, and restructure themselves.

However, in listening to stories in individual interviews I began to understand that some of the tasks family members performed were done not as a part of group functioning but to support an individual's goals during bereavement. This finding led me to understand that families play two critical roles during bereavement: 1) to engage in a process together with a shared goal of preserving family functioning through grieving, mourning, and 'restructuring family,' and 2) to support one another's individual process during bereavement. This second role will be further discussed in a following section. The elements of the shared family process identified in this study are, family grief (quieting), family mourning (creating the spirit of the child), and family restructuring (changed routines and roles, establishing a place for the child). These elements will be further elaborated in the following sections.

The Importance of Family Norms, Roles, Routines and Beliefs

The family process during bereavement is predicated on the norms, roles, and beliefs established by families prior to the death of the child. I have termed these antecedents. In this study, family antecedents were found to influence the process family members were able/willing to engage in as a group. Family norms were found to influence family communication patterns during bereavement and thereby influenced family members' ability to share with one another their experience. In the current study, families with norms that supported open communication engaged in a shared process during bereavement whereas those families with closed communication did not.

In this study, I asked families to tell me about their family rules (norms). I was told about a variety of family rules; some culturally based and others determined by the family itself. As in previous studies (Cimete & Kuguoglu, 2006; Doran & Hansen, 2006; Gudmundsdottir & Chesla, 2006; Fletcher, 2002; Saiki et al., 1994), I found that norms strongly influenced the practices of families during bereavement. In this study, all family members were Canadians of European ancestry and, with the exception of one mother, did not appear to have strong cultural norms that influenced their bereavement. Instead, the rules families operated under had been established when the couple came together and modified by them through the course of their relationship and family evolution. As well, illustrated in the stories of the Damant and Schmidt families, I found that family identity was created, not only through their norms, but was also contributed to by the ways in which families accomplish their daily tasks as previously reported by Langellier and Peterson (2006). The Damant family was having difficulty reestablishing their daily tasks and expressed that they were having difficulty figuring out what they now would be as a family especially when it came to paternal grandmother's role in their family. The

Schmidt family had to figure out what it meant to be "an all girl family" following the death of Mateo. In particular, Father had to learn how to continue in his mentoring role without the advantage of teaching activities of woodworking and soccer previously enjoyed with his son.

These examples further illustrate the effects bereavement has on family roles. Roles and family routines are considered important components in family functioning during bereavement (Shapiro, 1994; Rando, 1984). In this study, family roles and routines prior to the death influenced the family process during bereavement in a number of ways as seen in the family stories in Chapter 5. Of particular importance, is the willingness of family members to be flexible in their roles and the tasks they are willing to take on during bereavement to support family needs. But not all families have norms that allow for this flexibility in routines and roles as will be seen in the next section.

A further antecedent that I found to be important was the beliefs families held prior to the death of the child. While some beliefs were personal, such as those held in the Smyth family where members believed in an afterlife and the ongoing spiritual presence of the deceased child, other beliefs were based on the family's religious practices. In this study, the Schmidt and deJong families demonstrated how strong religious beliefs aided them during their process in bereavement. Together with cultural norms, religious beliefs have been found to influence family practices during bereavement (Cimete & Kuguoglu, 2006; Doran & Hansen, 2006; Saiki et al., 1994). My study adds to this evidence and further indicates support of Nadeau's (1998) finding of meaning making in families who have experienced the death of an adult. In her study, Nadeau found that when families hold strong, shared religious beliefs they were able to use these beliefs to aid in their process of meaning making. This point will be further illustrated in the section on family mourning. It is important to note, previously held norms, beliefs, roles and routines as found in this study were not always that beneficial to the family process during bereavement. This will be discussed in the next section.

When There Is No Family Process

While the purpose of this ethnography was to describe and understand the family experience and trajectory during bereavement, it is important to note that some families reported only individual processes during bereavement. Personal beliefs and family norms precluded a shared family process during bereavement, and for some families, the lack of family process even limited the context of family support. Most notably, when family norms did not encourage open communication including the sharing of strong feelings, families found it difficult to work together during bereavement. These norms, together with strong personal beliefs such as "a man must be strong for his family," could shut down communication in a way that the family could not process the death together. When this occurred, spouses reported feeling isolated, became estranged, and ultimately divorced resulting to an end to the family as it existed prior to the child's death. It appeared that, sometimes, family norms were hidden until the crisis of the child's death brought them to the forefront. Father Stewart reported that his alcoholism, which he reports was not recognized by him or his spouse as problematic prior to his son's death, was the hidden norm that did not allow him to deal with his feelings leading eventually to the demise of his family.

In the current study, four families reported no engagement in shared family process among family members who lived in the household. Mother Baker, however, reported that she and Aunt Choice (who lived outside the house) had engaged minimally in a shared process wherein they told stories of Helen. But without the engagement of the couple in the shared process, the family did not survive, perhaps because roles and routines could not be re-established. However, as this illustrates, for some family members, even in the absence of this shared process, the support of other family members was crucial as context for individual family member's process. Mother Fraser and Mother Barnes reported that family members outside the house took part in rituals of remembrance but when they did so this was in the context of supporting Mother not as a mutual celebration of the child as occurred in the families wherein a shared family process occurred. When families served as context this support allowed family members to do their own individual work of grief and mourning, leading some to self-reformulating. This individual process during bereavement is seen in the within case analysis in Chapter 5 and provided crucial information for constructing the coherent family stories.

Family Grief: Quieting

The findings of this study suggest that when families experience the death of a child, the members who reside in the household engage in a process I call "quieting" following the child's funeral/memorial service. During this time families create an atmosphere where members can experience their own sense of loss and attend to their needs as a family. Families reported that they reduced their social contacts, including their involvement in volunteer work, and reduced their levels of activity within the household, including a reduction in housekeeping routines. When possible, even employment routines were put on hold. Some families reported reducing their levels of verbal communication within the household as well. Families reported that their routines came to a halt as much as possible so that family members could preserve their energy for engaging in their individual and family processes during bereavement. Participants were seen to negotiate new ways to maintain the household recognizing the shifting capacities of family members to accomplish the work of the household.

When viewed in this way, quieting creates a shared inner experience of family or tone that can be related to the internal experience of individuals that is referred to as grief. When I entered the homes of participant families who were experiencing this element of the shared family process, I was aware of this tone. Family members spoke in soft voices when they told of their experiences, demonstrating little affect other than deep sorrow. Their engagement with one another lacked the vibrancy demonstrated in families who were no longer reporting this quieting.

While lack of energy in individuals (Parkes, 1975) and reduced activities (Rando, 1984) have been reported in the clinical literature these responses have not been conceptualized as family grief. When the term 'family grief' is used in the literature, it is most often done so by family therapists who are reporting on family interventions during bereavement. The term is generally meant to convey the intra psychic process individuals undergo in the context of families and how family members adjust their relationships during bereavement (Lamberti & Detmer, 1993; Shapiro, 1994). Further, a theoretical exploration of families and loss conducted by Gilbert (1996) suggested that as we view families we most often see individual members in very different states of grief. Gilbert added that to say families grieve would be to imply that all members experience a common set of emotions and that when one member's grief ends, family grief ends. This led Gilbert to theorize that "*Families do not grieve*. Only individuals grieve. This is done in a variety of contexts, one of which is family" (italics in the original, p.273). The current study suggests that families have an inner experience, or tone, that can be referred to as family grief; and that this inner (to families) experience is more than context. However, it is important to note that quieting was reported only in those families who were able to engage in this shared process.

Family members describe their initial reaction to the death of their child as one in which their sense of the world as a safe place has been shattered; nothing makes sense any more (Rando, 1986). In the current study, family members suggested that they needed to redefine "who we are as a family." Meleis and Lindgren (2002) have suggested that families need to create a cohesive social unit in the home before they can reengage in the community, and rebuild their sense of harmony and safety that results from this cohesion. It appears that the family process of quieting may give families the emotional space to begin the next phase of shared process; that of family mourning.

Family Mourning: Creating the "Spirit of the Child"

In the current study, family mourning was found to be a shared experience wherein family members worked together to address the question "who is this child to us as the family we are now?" and in so doing create the "spirit of the child"—an image of the child that culminates in an ongoing place and role for the child in the family. This element of the shared family process was often a very active one in which many members of the family were engaged in telling the child's story, in rituals and celebrations of remembrance, and in the shared experience of making meaning of the child's life and death.

Telling the Child's Story

Families in my study gathered to tell the story of their child. Often the stories began as the family prepared for the funeral/memorial service with the gathering of family members of various relationships. Many family members took part in this element of the shared family process as was exemplified in the family interview of the Smyth family. Families reported that most commonly not only parents and siblings took part in telling the child story but grandparents, aunts, and uncles (including the family of choice) added tales of the child. In this way the image of the child was extended and contributed to the family's understanding of the important role the child played within their family.

While previous research on family (Doran & Hansen, 2006; Gudmundsdottir & Chesla, 2006; Fletcher, 2002; McClowry et al., 1987) and individual bereavement (Klass, 1995; Rosenblatt, 2000; Talbot, 2002; Wheeler, 2001) report on telling the child's story, the current study extends our understanding of the way in which mourning is used by families and how their shared storytelling about the child, both the living child and the events surrounding the death, creates the "spirit of the child" which is used during their family restructuring to incorporate an ongoing place for the child. Participants in this study suggested that another important dimension of telling the child's story is seen in their use of "reminders" such as viewing photos and videos, making scrapbooks and collages, and other activities such as quilt making and stained-glass work. These reminders not only presented families with the opportunity to talk about the child, adding to the important place the child held and will continue to hold in the family, but assisted siblings who were too young at the time of the death to come to know the child and to understand the important place the deceased child holds in the family. Further opportunities to tell the child's story were present when families gathered for rituals and celebrations.

Rituals and Celebrations of Remembrance

Findings related to rituals and celebrations of remembrance in the current study support and add to the results from other studies on the importance to families of these events in establishing an ongoing relationship with the child. As other studies have indicated, these rituals and celebrations may be private or public, but they tend to occur immediately following the death (Cimete & Kuguoglu, 2006; Doran & Hansen, 2006; Gudmundsdottir & Chesla, 2006; Fletcher, 2002; Saiki et al., 1994; McClowry et al., 1987) as well as annually thereafter. These rituals and celebrations offer opportunities for families to achieve ongoing support for their loss (Doran & Hansen, 2006; Fletcher, 2002; Saiki et al., 1994). Participants, in this study, offered an additional insight previously unreported in the literature when they indicated that these rituals and celebrations held particular importance for family members during the first few years following the child's death but as the child's place in the family became more integrated into the family, these rituals and celebrations of remembrance seemed less necessary. Some participants indicated that fund-raising activities to honor the child became part of their annual rituals to honor the child and keep their memory alive. These activities also gave parents the opportunity to feel that they were giving back to others, particularly the medical community, who had assisted them at the time of the child's death.

In the bereavement literature, one commonly reported activity of remembrance is visiting the grave. While not all families in the current study found this to be a meaningful experience, many families found that being at the cemetery brought a sense of closeness to their child. A particularly interesting story was told by one family who had chosen cremation as a way to ensure that they would always have their child close. This family expected, due to father's employment, that they would have frequent moves around the country and did not wish to bury their son in a place that they would not be able to visit. In this way cremation provided a meaningful way to "carry Patrick with them." Further research is needed to establish the extent to which the current mobility of families, caused often by work opportunities, influences the kinds of rituals that are perceived, and experienced to be useful or not. This issue is exemplified in the recent controversy of the location of the grave of a RCMP officer killed in the line of duty, in which the wife of the officer wanted her husband buried in a special RCMP cemetery in Saskatchewan while his parents wanted his body to remain buried in their hometown in Alberta. Perhaps norms, traditions, and rituals are changing to reflect the mobility of the population. This is important for the evaluation and implementation of clinical strategies for bereaved families – where once the grave might have represented the tangible connection to the child, cremation, and the keeping of ashes may be a useful alternative for many mobile families.

General family celebrations, such as those that occur at key family holidays or on birthdays, often included a symbolic representation of the child whether it be the star candle burning on Christmas Day or the acknowledgement of the "empty space" (McClowry et al., 1987) representing the deceased child seen between the bride and her sister. Other times of remembrance occurred on the day of milestones that the child was not able to experience—the day she was to begin first grade, the day he would have graduated from high school, or the day her brother's first child was born. In the current study, parents reported that on these special occasions they would wonder what their child would have looked like now and what s/he would have been like. These thoughts occurred during private moments and were shared only between spouses.

While many of the findings of the current study in the area of rituals and celebrations of remembrance have been reported previously in the literature, it is in conceptualizing this component together with telling the child's story and the shared family experience of meaning making as family mourning with the goal of creating the spirit of the child that a further understanding of the family experience during bereavement is created.

Meaning Making

During the family interviews, participants often reported their experiences in making meaning of the life and death of their child. Exemplified by the deJong family, this family meaning making process may begin immediately on hearing of the child's death. Mother and Father deJong were still in the emergency room when they decided that they would actively pursue the existential purpose of Hannah's death. This conversation began the very active work of Father and Mother's speaking to others about the importance and meaning of life even when it is so short. Further evidence was observed in this study within the family interviews as members contributed their personal thoughts on the meaning of their child's life and other family members agreed and further clarified the importance of these short lives.

While no studies with the family as unit of analysis when a child has died have directly explored the process of meaning making, Nadeau (1998) studied families who had experienced the death of an adult member. She found that making meaning of both the life and death of the deceased person involved interactions between family members, as well as transactions with the community based on societal beliefs and values. The sharing of family members during their family storytelling sessions influenced, and was influenced by the experience of grief and mourning of other family members, as well as the societal belief system in which they resided. The current study confirms the findings of Nadeau and extends them by suggesting that following the death of a child, families also engage in storytelling that contributes to the meaning making of family members. In the current study, families also reported that meaning making contributed to the sense of hope for their future as a once more vital family , a result of family work also described by Vandall-Walker (2007) during the crisis of a family member's critical illness.

Restructuring Family

Family mourning to create the spirit of the child is brought to an end when families have a place for the child within their family structure and new roles and rituals that allow them to restructure their family for continued functioning. However, data from the current study suggest that this family restructuring does not unfold in any given order and the process has no predetermined time frame or limit. In the current study only two families reported a restructured family while a third family reported that they felt they had established an ongoing place for their child but we're still working to establish the new roles and routines needed to identify them as a restructured family. Some of the families had not yet experienced a length of bereavement wherein family restructuring would be expected.

Two of the three families, who reported evidence of family restructuring, suggested that they had an ongoing place for their child after two years of bereavement. In both families, very active work of creating the spirit of the child began almost immediately on hearing of the child's death and was guided by a strong religious belief system that allowed them to find meaning in the child's short life through their belief that each person was given a purpose for living by God and when this was accomplished, that person was "called home." The third family in this study who reported a restructuring of family did so 10 years after the death of their child. This family too had very actively created an ongoing place for child within their family.

These three families further reported that they had worked together to establish new roles and new routines following the death of their child. One family reported the need to reestablish family routines within two weeks of the child's death and began to actively do so but in the two years since the death of their daughter they were still engaged in establishing their routines and roles and in particular making decisions on whether to have additional children that will defined who they will be as a family in the years to come.

The second family reported that after one year they felt that they had adjusted family roles and routines to allow them to function as the family they now were. The third family in this study reported that it was 10 years after the death of their child when they experienced the readjustment of routines and roles that allowed them to redefine "our family" and the "work we do together" as reported by Langellier and Peterson (2006, p.470) to be important work of families. All three families continue to carry the spirit of their child with them into their ongoing life.

As seen in the current study, during family restructuring families create a place for their child, referred to in studies of individual bereavement as establishing a "continuing bond" (Klass, 1996). Where once detachment from the deceased person was thought to be needed in order for the bereaved person to re-engage in life (Freud, 1917/1957), in the last two decades theoretical and empirical studies suggest that family members continue a relationship with the deceased child—a "continuing bond"—(although the relationship differs from what it would be if the person were still alive) while being able to go on with their life (Klass, 1996; Rosenblatt, 2000; Worden, 1991). The current study supports these findings and extends our current understanding to the importance of this bond in the family as well as in the individual. This evidence also supports the findings of McClowry et al. (1987) who suggested that families, 7 to 9 years bereaved, created an "empty space" which allow them to continue to relate to the child who had died, to integrate their pain and loss into their life, and to find new satisfaction in living. The elements of the shared family process during bereavement, including creating a place for the child within the family contributes to the family's ability to continue to function following the death of a child. In further support of this conclusion was the evidence seen that when there was no shared family process, even in long-term bereaved families, no place for the child had been created in the family when these families dissolved when divorce took place. The spirit of the child dwelled only in the hearts of individual family members.

However, an important further finding was reported by one long-term bereaved family where no shared family process had taken place and as a result the family as it had been at the time of the child's death had ended. Creating the spirit of the child was done with a new generation of family members when Mother's grandchildren accompanied her to the cemetery for her annual remembrance ritual. By taking part in this ritual, her grandchildren worked to create an ongoing place of the child, moving it from within grandmother alone to a place within the ongoing intergenerational family.

Family as a Context of Support

The current study lends evidence to the importance of the role of families in supporting each other through acts of kindness. Further, this study extends our understanding of family support by identifying two additional ways that family members provided support to each other, specifically through creating space for individual ways to mourn and in loving acts. Much of this support was given by extended family members who lived outside the household and in this way played a very active role in contributing to the family process during bereavement. Grandparents, in particular, often considered support of their bereaved children and grandchildren their main duty during bereavement. This finding echoes those of Doran and Hanson (2006) and Ponzetti (1992).

Creating Space

Participants in this study acknowledged that other family members often grieved and mourned in ways very different from their own. Family members reported that, while they did not always understand the way others mourned the child, they tolerated these behaviours when needed in order to create space for the other's experience. At times, family members kept their own pain hidden in an effort to protect another family member from this pain in an effort to minimize worry and anxiety. This was shown when one family member supported another whose way of mourning was to turn inward and distract himself with TV by sitting silently with him. For another family member, creating space meant taking a second look at a judgment she had made regarding the love another family member felt for their child. For siblings, creating space was seen as they gave parents space for self-care instead of relying on their parents to accomplish the usual household and parenting tasks. At times, creating space required more than the passive acceptance of another family member's need to grieve differently and at these times further support is given through kindness and loving acts.

Kindness Acts

Kindness acts are most frequently seen in the help family members give to one another with the chores of the household. As reported in other studies, family members, often grandmothers and aunts (Meert et al., 2005; Ponzetti, 1992), provide household tasks as a means to support bereaved parents and siblings. Grandmothers took care of young siblings when Mothers found it impossible to get out of bed. Aunts cooked meals and returned phone calls. These acts also extended to providing financial support when parents could not maintain their employment and had no benefits to provide income. This finding confirms those of Doran and Hansen (2006).

For some families in this study, these kindness acts were abundant while for others they seemed to the bereaved family member to be in short supply. Some participant families reported that they received support not only from extended family, but as Doran and Hansen (2006) reported, additional support came from their church and cultural community as well. Extending the previous findings, this study included participants from “families of choice” (individuals who were defined as family members by participants) and found that these family members played a crucial role in supporting bereaved parents and siblings, especially when "blood/legal” family was unavailable due to geographical or emotional distance.

With the exception of one sibling, families in this study did not consider the deceased child's school community to be family members. Nonetheless, for a number of families in this study the school community played a crucial role in supporting families following the death of a child. When children had been old enough to attend school, the school community was often actively involved in supporting the family through fund-raising and memorials in the child's name. When this occurred, families reported feeling less isolated and freer to speak openly of their child with these community members. It appears that schools have become more responsive to the need of bereaved families to have their child acknowledged. The two families of school-age children in this study who had been bereaved for more than 14 years bereaved did not mention the involvement of the child's school in remembrance activities. This may indicate a cultural shift away from our intensely "death denying society" as reported by Rando in 1984 and warrants further investigation.

Loving Acts

Family members in the current study reported that at times they consciously chose to provide support to another family member while knowing that their own grief needs would go unmet. I refer to these as loving acts. While similar to kindness act, loving acts include an element of self-sacrifice in service to other family members. The finding of loving acts is original in this study. Most commonly, loving acts were reported within the marital or parent-child dyad. It appeared that spouses were willing to put their own needs on hold temporarily to support their spouse when they believed that in doing so their wife/husband would be free to focus on their troublesome thoughts and feelings and return more quickly to their pre-loss functioning. In this way, the family member performing the loving act hoped that family would be maintained. This finding lends evidence to the extensive study of parental grief by Rosenblatt (2000) and his finding of the importance of the marital dyad as a resource for bereaved parents. One father, who divorced some years after the death of his son, acknowledged that following the death he and his wife no longer performed loving acts for each other—a component of their marriage that had been in evidence before their son's death. In realizing this during the interview, he remarked that of all the things that families do for each other during bereavement it is these loving acts which he feels are critical and need to be continued.

However, it is not only within the marital dyad that loving acts occur. Siblings interviewed in this study all reported on the protection they gave to their parents following the death of their brother or sister. This finding lends support to studies to the parent-child interaction reported by Davies (1991; 1999) who focused on the detrimental aspect this could have on children. Further, even young children in this study were found to provide support to their parents extending the current research on the role of family support during bereavement.

The findings of this study demonstrate that through the shared process of families to create the spirit of the child, and the supportive work of family members one to another, most families are able to restructure—creating a place for the child, and readjusting their roles and routines to fit their new life without the earthly presence of their child. But the family process during bereavement requires time, energy, and just effort on the part of family members.

Conceptualizing the Family Process during Bereavement as Family Work

During the course of this study, I was struck by participants' words relating to how much energy grief and mourning required and how exhausted they felt. It is in this way that I recognized that "work" was taking place both on an individual and family level. In the family literature, when family work is studied it is most often in terms of employment outside the home, or paid work that produces the family income. Radin (1996) distinguishes between "labor" and "work" referring to labor as work that is done to provide income and contributes to the economy, whereas work can be about making money but it also is a form of giving; it cannot be "separate from relations with other people" (p. 105). Most commonly, labor is thought to be motivated by pay, whereas work is not (Folbre & Nelson, 2000). Folbre (1995) suggests that not only labor, the most commonly reported type of work in the literature, produces an economic benefit to society, but it is also unpaid work that is important to families. Families are said to engage in both paid labor, as well as "caring labor" wherein they take "the concerns and needs of the other as a basis for action" (Tronto, 1993, p.105). They must accomplish the unpaid work of caring for each other on a daily basis and in times of need that is "part of families' lived experience" (Keating, Dosman, Swindle, & Fast, 2007, p. 178). This unpaid and invisible family work includes practical chores of maintaining the household including childcare, housekeeping, meal preparation, laundry, outside work, personal care, and transportation of family members. This unpaid work goes on day to day but must also be accomplished even in times of family crisis in order to sustain families (Beaujot & Liu, 2005; Folbre, 2004; Meleis & Lindgren, 2002; Secret, 2007; Thompson, 1991; Zvonkovic, Solomon, Humble, & Manoogian, 2005).

While these practical aspects of family work were present in the current study, the work of families is seen as having an additional dimension which was described in the classic work by Strauss et al. (1984) as one of providing support on an emotional level. More recently, this type of caring for others has been described as work that family members do that "coexists with numerous other roles in an individual's life" (Martin-Mathews & Phillips, 2007, p. xxiv) and may indeed be the essence of family life particularly in families where the work of caring for one another is based on reciprocity, altruism, and responsibility (Folbre,1995; Mayo, 2001). It is within this conceptualization of work as providing care within families that the processes family members engage in during bereavement can be understood as family work.

In this study family work was done in all elements of the process. The period of family grief is a time, as Vandall-Walker (2007) suggests, when families work at waiting—for a time when they can understand their pain and hope that one day they will again feel whole enough to re-establish household routines and communication and reengage with their social network. This was exemplified in the story of the Anderson family, usually a busy family with lots of social connections. But, as they tell their story, it is obvious that they have had to bring a quiet to their family, hoping and waiting for the day when their pain will diminish.

In family mourning, families work together to accomplish the emotional work (Zvonkovic et al., 2005) of telling stories, performing rituals and celebrations, and making meaning in order to create the spirit of the child which will produce the child's ongoing place in the family. This family work can best be described as "*kinwork* that knits households together to create and maintain family, community, and work ties through talk, rituals, and celebrations" (Langellier & Peterson, 2006, p.470). Evident in the Myhre family is the work of family storytelling and ritual that is creating the spirit of Ray, leaving little time or energy for other more routine family activities, especially for Sister and her family.

When family serves as context to the individual process, family members engage in during bereavement, family work is seen in abundance. While this is often the kinwork of support has been described as "women's labor of love and care" (Langellier & Peterson, 2006, p.470), findings from this study suggest that this work of “love and care” is not limited by gender or age but is indeed most often engaged in by all family members. Family support is work about "meeting human needs and creating human dignity. . . .[through] good work [that] is something of use or value to the person who does it and for whom it is done" (Mayo, 2001, p. 349). Further, Langellier and Peterson reported that family survival depends on the work of care of all family members so that the many tasks of family are accomplished. This notion of work was best exemplified in the current study in the Smyth family where many family members contributed acts of love and kindness but allowed space for the different expressions of grief needed by family members.

Methodological Challenges in Studying Family

Integrating Individual and Family Experiences

When first approached, families appear to display a collective consciousness, suggesting that they have organized themselves to deal with the world based on their commonly-held values and beliefs. It is only over time that the outsider becomes privy to the variations of individual members interests, experiences, qualities, and beliefs (Daly. 1992). During this study, I conducted family interviews wherein I was privy to their shared assumptions about their world and their shared perceptions of their experience of losing a family member. But, when I interviewed each individual family member, I became aware that the assumptions and perceptions that guided their transactions in the family interview (Gubrium & Holstein, 1990) did not reveal the entire experience of their grief and mourning following the death of child. While the individual interviews always revealed differences in the experience due to the nature of the relationship each family member had with the deceased child, most often the basic elements of the "story" were the same. This was exemplified in the Schmidt family story when Mother spoke about her connection with Mateo as one in which he was carried "on her hip," while Father spoke of his loss as mentor, and Sisters 1 and 2 spoke of their loss of a big brother. Generally, family members spoke more and at a deeper level about the pain they had experienced in bereavement in their individual interviews. These interviews added a depth to my understanding of the effects the death of a child has on various family members and how it affected the roles and routines of the family.

In the family interviews, I could see how family members interacted with each other in this particular context. As families built on each other's thoughts in "telling the story," a picture of family bereavement was created as a whole and gave a more coherent picture than I would have seen if only the parts had been examined through interviews with individual members (Larzerlere & Klein, 1988; Gubrium & Holstein, 1990). But, at times, as may be expected, the privileged access family members have to their life "backstage," the hidden side of family, was revealed to some extent through these individual interviews. As an example, it was seldom recognized in the family interview how often or the extent to which surviving siblings put their own needs on hold in order to protect their parents. At times the stories family members told in their individual interviews added components that were somewhat contradictory to those in the family interview. Most often, these components could be added into the family story in such a way that increased the understanding of the experience of family bereavement. However, on rare occasions these differing opinions could not be reconciled and led me to consider the ethics of sharing confidential information in the family story. Through studying family as the unit of analysis I sought a private level of interaction where some information was only available to certain family members or subsystem (i.e. spousal, parent/child, siblings) (Greenstein, 2006), but by adding individual interviews I gained access to further private information that at times led to ethical dilemmas. I will discuss the ethical issues in the following section.

Ethical Considerations

Ethical issues can arise in when conducting both family and individual interviews. These differences were most clearly seen during the interviews of the siblings. The first ethical dilemma I experienced occurred in a family interview where it appeared that perhaps the siblings were being mildly coerced into taking part in the interview. I became keenly aware (even after reminding them of their right to refuse participation and their further agreement to take part) that my probing for their experience had limits in order for me to feel that I was not adding to the possible coercion. While the vast majority of siblings needed reassurance that the content of their individual interviews would be kept confidential, I was particularly careful when it had appeared to me that siblings may have felt some family pressure to participate, to reassure them of their right to withdraw and that the information they gave would be held in confidence. Again, in the individual interviews I felt some constraint in the probing I did as a result of what I felt was a reluctance to participate.

Even for those siblings who did not seem reluctant, behaviors such as glancing over their shoulder to make sure that their parents were not in the area and overhearing their remarks could be seen. One sibling began the interview by stating that the opinions given in this individual interview would demonstrate some differences from what I had heard in the family interview, and indeed they did. This made it difficult when constructing the family story to decide what portions should be included to reflect the experience and what portions should be excluded. On one of these occasions, I felt that to report the information in the family story would be a clear breach of confidentiality and chose not to report it. Fortunately, in this instance, the family story was not essentially changed by this exclusion, but had I had permission to report on this information it could have added a further depth of understanding of the sibling's experience. On another occasion however, to omit the information would have given a very different appearance to the family story. In this circumstance, I prepared the family story including the information but gave it only to the sibling to review and further discuss with me. Following that discussion, permission was given by the sibling to include this information in the family study. The reflection that occurred did alter the family – a classic case of qualitative research breaching the boundaries between research and therapy.

Many of the participants did tell me of the beneficial results of talking about their experiences with me and with their families. To a large extent I was an outside listener, albeit one committed to understanding and articulating their stories. Unfortunately, pursuing the notion of the effect of being researched on the family experience was beyond the scope of this study. However, a researcher conducting family and individual interviews must give consideration to these issues of confidentiality in planning and conducting their study. I believe that my skill as a family therapist in the area of bereavement, my education as a social worker, and my ability to guide and support family members as they reflected on their story was essential in conducting this study in an ethical manner.

Constructing the Family Story When Not All Members of the Family Take Part in the Study

The richness and complexity of family life is better understood when data from various family members are gathered (Gubrium & Holstein, 1990), but in this study some family members were excluded which I believe reflected important processes in these families. Family discourse is an active process. This process can lead to defining family through observation of these interpersonal relationships (Gubrium & Holstein, 1990). The notion that family is "whoever they say it is" presumes that 'they' will agree on who family is. But, family members don't always agree on who should be designated family. An example of designation of family is present in the Myhre family. Mother Myhre insisted on excluding Father during Ray's illness and from participation in his funeral. It appeared Father's participation in the study was never a question for Mother who now saw Stepfather as having the designation of "father". One can only speculate on the further understanding that I would have obtained of family bereavement had Father Myhre, who was estranged from his sons, been interviewed.

Allan (1980) has suggested that "it is often difficult to know what weight to assign to conflicting accounts, intuitively, it seems plausible that a more reliable picture will emerge as the bias in one version may be balanced by the other" (p. 206). Grandmother Damant was excluded from the family interview due to the break in family relationships caused by her presence in the accident which resulted in Ben's death. Had she been available to be interviewed, I might have obtained information that conflicted with the family's account of her responsibility in the accident. A more reliable picture of parental/grandparental interaction could have been obtained, adding a further understanding to the experience of grandparents. Had her account been available together with the account of the Schmidt family grandparents, a richer data set would likely have emerged showing the contrasts in bereavement due to the families' assignment of blame.

In the current study, families decided who they would ask to take part in the interview. Gubrium and Holstein (1990) suggest that "family discourse is not just a mode of communication, but also assigns meaning to the actions we take on behalf of social ties designated familial" (p.14). For families who chose to limit participation to members of the household, information on the boundaries of their family seemed to be evident in this action. This is most clearly seen in the Jones family where the "independence" of family members was further qualified by their exclusion from participation—Mother and Father had not even thought to include Mother's sister and parents in the study. While my study findings indicate the various levels of involvement of extended family members, clearly these findings would have further enhanced these findings had these members taken part in the study.

Studying family holds many challenges, especially when family is the unit of analysis. But in approaching family bereavement through two units of analysis, my findings provide a fuller understanding of the phenomenon than has been reported elsewhere.

Limitations of This Study

As with any qualitative research this study is limited by the timing of the study and participant selection. Bereavement is an emotionally difficult phenomenon to study and participation is limited to those individuals who are willing to speak of their experience. As well, interviews require the use of words and in bereavement it may not be possible for participants to find the words to express the fullness of their experience. Further, many bereaved people (as seen with grandfathers in this study) are not willing to speak of the experience because of the pain in remembering. In the current study, participants most often spoke of the death of their child as a transformative experience. One cannot conclude that such an experience would be universally transformative. It may well be that this is a result limited to bereaved families who are willing to participate in studies such as this one.

While the findings of qualitative studies are not general to the population of all bereaved persons, the goal of this ethnography was to understand the breadth of experience of this phenomenon. All participants in this study were white, middle-class, Christian, and Canadians of European ancestry, and who lived in traditionally nuclear families during the life of the child who died. It would be expected that for persons of different ethnic and racial backgrounds or different religious beliefs, and those in non-traditional or non-nuclear families a different ethnography would emerge; further research is needed to capture the diversity of other cultures. By asking the family spokesperson to determine "who is your family" for the purposes of the interviews, family membership was limited to the conceptualization of family of the spokesperson and may have missed persons whom the deceased child might have considered family. During the course of the study, it became obvious that certain family members, some of whom may have been critical to understanding the family experience had not been invited to take part in the study. As well, some family members chose not to take part. Hence, the definition of the bereaved family is limited in this study. Of particular interest is further exploration of my finding that the engagement and contribution to family restructuring is dependent on the whether or not the family member resides within the family home. While it might be expected that other cultural or ethnic groups may show cultural variations in restructuring, it is necessary to explore the extent to which these findings are pertinent to non-nuclear and non-traditional families such as blended families, gay/lesbian families or those where extended kin, such as frail grandparents, reside within the home. Further research is needed to explore the facets limited in this study.

Implications of the Study

There are some significant theoretical, clinical, and research implications resulting from this study. This study adds to the perspective of the importance of family in the present bereavement theory. In particular, the study findings pertaining to family grief require further investigation to explore the finding of quieting in other experiences of death such as that of a parent or spouse. As well, while this study proposed to examine the culture of families who had experienced the death of a child and not the process of family bereavement, study findings suggest that families do experience a process which unfolds over time. Further studies with the expressed purpose of investigating a family process of bereavement are needed. The study findings indicate that family bereavement can be a transformative experience for families. Further theoretical work on the relationship between this possible growth and the theory of contextual resiliency is needed. The conceptualization of the bereaved family was limited by family member's definition of membership in their family as well as the willingness of identified family members to participate. Further studies to explore the definition of family during bereavement are needed to enhance understanding of family membership. While this study produced some findings on the intersection between individual and family bereavement, further studies are needed to explore this intersection over various cultures and bereavement experiences.

In current clinical practice, bereavement is most often addressed at the individual level of experience. This study suggests that interventions aimed at involving family groups in "telling the story", rituals of remembrance, and meaning making may enhance practice with family members who have experienced the death of a child. As well, the support role of extended family found in this study suggests that encouraging the involvement of numerous family members and suggestions to bereaved parents and siblings to reach out to these members for help would be beneficial.

Education aimed at helping professionals needs to include information on the important roles families play in bereavement. As well, public education focusing on the family effects of bereavement and the supportive roles family members can play in this process may help to break the isolation many bereaved parents and siblings currently experience following the death of a child. Bereaved family members may benefit from the information provided in this study on the importance of the benefits of quieting as a way to focus on the family work of mourning, as well as on the support especially through loving acts. While it may not be possible to change family norms in the midst of this crisis, this information may equip family members with the hope that they can influence the outcome of their bereavement experience.

How This Research Has Changed My Assumptions about Family Bereavement

Throughout my career as a social worker, and especially when practicing in the area of bereavement, I have known that my greatest learning about human nature comes from listening to my clients. Shapiro (2008) states that "a culturally informed ecosystemic approach to grief and growth considers research, practice, and experiential perspectives on recovery while emphasizing accountability to outcomes of interest to the bereaved themselves, for both ethical and pragmatic reasons" (p.42). While I have always attempted to introduce clinical theorizing into my work with clients and to stay current on practice theories, I have not always thought about incorporating the learning from general theory/theorizing into the practice setting letting it form a framework for assessment and intervention. I have practiced most often from the perspective of "the little picture" of the individual, ignoring perhaps the "middle picture" containing family, and certainly ignoring the "big picture" of general theory. While in social work I was educated to always consider the person in their environment and that "private troubles" are not exclusive to the individual, I have not always considered how the very personal experience of losing someone you love is affected by family relationships. It may have been only when the individual client spoke of their family that my attention turned to this level. In my practice, I would invite families in and encourage individual clients to invite their family members into the counseling sessions. I now am reaffirmed in my (formerly held weak) belief that when family members can hear one another's struggles and hopes, increased family communication and support can take place. I would ask more questions about the client's support network and encourage them to accept all help that is being offered and to reach out and ask for help from others. Shapiro (2008) offers good advice to the practitioner when she reminds us that "respecting the motivations and age-appropriate self-determination of grieving individuals in light of their interdependence, helping them nurture relationships, sustain capacities to love, remember and hope in the presence of death and loss, all consistently generate better health and mental health outcomes for bereaved of all ages than any search for psychopathology" (p. 42). While I feel that I never practiced from a perspective of seeing bereavement as pathology, I do not feel that I was fully aware of the strength of family in aiding the individual mourner or how this family level intervention could be strengthened for the benefit of all members. In particular, this study has emphasized the diversity of kinds of individual and family work that may occur – and that these are not inherently good or bad, but a result of antecedent norms and values. As a therapist, it would seem to be important to explore with families and individuals the extent to which these pre-existing norms are influencing their current experience, and strategies to strengthen – or challenge them.

As a social worker, I am ethically bound to address the "big picture" issues facing individuals and restricting their well-being. Looking at grief and mourning as individual pathology creates one of these restrictions. Shapiro (2008) further reminds us that "practitioners responsible for bereavement care must also consider the practice settings serving as starting-points for knowledge and professional accountability to child, family, and community" (p. 43). Family can be a powerful place of intervention during bereavement. What I have learned about the importance of family and family level intervention needs to be shared within the professional and bigger community so that families experiencing the death of a child can receive the understanding and support they require at this unexpected life transition.

What I have learned most in doing this study is not just about family bereavement. What I have learned is that the more I seek to understand, the less I "know". As a result, I have been reluctantly pulled from the place of practice into the world of academia. To further advance family bereavement practice, I must become a "perpetual learner" through research, practice, and teaching incorporating what future clients will teach me, what future students will teach me, and what future research participants will teach me. On a personal level, I will experience death of those I love and must learn from these experiences and be willing to learn from them. One belief that has not changed for me while conducting this study is that suffering is a place in the human experience that can be beneficial to our growth if we allow it to be but even though it hurts. As a helping professional, I find it painful to sit with those who share their grief--I do not like that this suffering must be done. I must find the courage to value the suffering and do what little I can to help those in pain continue to hope that one day their pain will lead to growth. I must learn from my participants in this study and the researchers/theorists/clinicians who have shared their knowledge through their writings not to hurry this necessary human process. I appreciate and hold dear their lessons.

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APPENDIX A

DEMOGRAPHIC CHARACTERISTICS RECORD

Name of participant	Gender	Relationship to deceased child	Religious affiliation	Ethnicity	Level of Education
Gender of child	Cause of death	Age at death	Date of death		

APPENDIX B

GENOGRAM

Instructions: Please make a model of your family using the following symbols

Males □ (square) Females ○ (circle)

Indicates a strong relationship ━━━ (solid bold line)

Indicates a medium relationship ——— (solid light line)

Indicates a weak relationship ▬ ▬ ▬ (dashed line)

Indicates no further contact .... (dotted line)

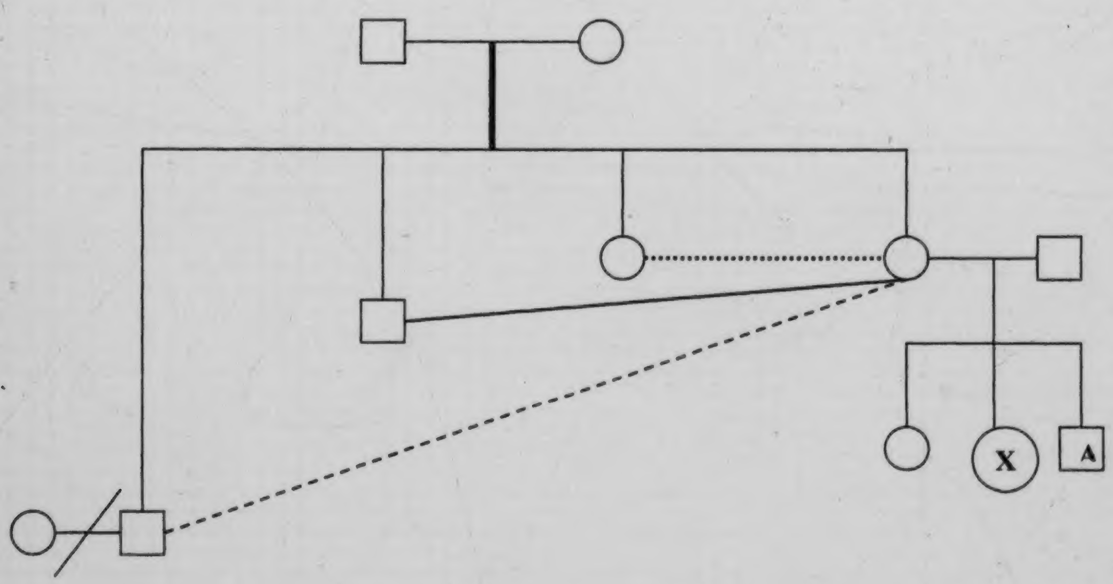
Include three generations of family including: first name, date of birth/death/entry into family

For those members who have died (put an X through their circle/square)

For those members who have divorced (put / through their connecting line)

For those members who have been adopted (put an A in their circle/square)

Example:



APPENDIX C
LETTER OF INVITATION
THE COMPASSIONATE FRIENDS

Dear Member of The Compassionate Friends ,

My name is Marge Berg-deJong. I am a graduate student in Family Studies at the University of Alberta. I am doing a study on how families mourn following the death of a child. As you all know, the death of a child affects every member of the family. This study will look at the experience of the whole family as they work to cope with the changes the death of a child brings. Being in the study will involve two family interviews (about 90 minutes each) and one with each family member, including children 12 and over. This study has been approved by the University of Alberta Research Ethics Committee (file # ------).

If you are interested in more information or volunteering please call me at (780) 452-0594 or email at maberg@ualberta.ca. Thank you for considering this request.

Sincerely,

Marge deJong-Berg
Ph.D. student, University of Alberta

5

APPENDICES D

FOR USE BY PARTICIPANTS RECRUITED IN THE COMMUNITY

STUDY INFORMATION SHEET
CONSENT FORM (ADULTS)
CONSENT FORM (CHILDREN TO BE SIGNED BY PARENT)
INFORMATION SHEET AND ASSENT FORM FOR CHILDREN (ages 12 to 18)
CONSENT FOR PHOTOGRAPHY AND USE OF AUDIO RECORDING

APPENDIX D

STUDY INFORMATION SHEET

Study title: *Family mourning: The experience of families when a child dies*

Researchers:

Co-Primary Investigator	**Co-Primary Investigator**	**Co-Investigator**
Priscilla M. Koop RN PhD	Judith Spiers RN PhD	Margaret A. deJong-Berg MSW
Associate professor	Assistant professor	Graduate Student
Faculty of Nursing	Faculty of Nursing	Department of Human Ecology
3rd floor CSB	3rd floor CSB	3rd floor Human Ecology Building
University of Alberta	University of Alberta	University of Alberta
Phone: 492-2962	Phone: 492-9821	Phone: 492-7789 (B) 452-0594 (H)
FAX: 492-2551	FAX: 492-2551	FAX: 492-2551

Purpose: The purpose of this study is to describe and explore how families mourn the death of a child in their family.

Methods: We will arrange a time to meet and talk about your experiences when your child died. I will meet with your family twice and with you as an individual once. These interviews will be audio-taped. I will ask you to show me photos or mementos of your child that are important to you. I will ask to scan the photos and photograph the mementos. With your family we will talk together about what family is to you and how the loss of your child has affected your family. Your family will work together to draw a map of your family and describe your family.

I may ask to talk with you a second time to follow up on some interesting ideas from your previous interview and to make sure I got your story right.

In another interview with just you, we will talk about the feelings you have had since your child died and how what your family did during this time affected your grief. Children may wish to tell their story in drawings or writing to relate their experience.

You can choose first to talk with me alone or as a family, whichever you think is best. If we talk alone first, what you say will just be between us and I will not tell these things to your family unless you give me permission.

These interviews will take place in your home or my office, whichever is best for you. I would be happy to see a photo of your child or some of the special things you have to remember her/him. I may like to take a picture of these things or record them on videotape. If you do special things like going to his/her grave as family or have remembrance ceremonies, I would like to observe these.

The family sessions will take about 90 minutes the first time and 60 minutes the second time. I will talk with you by yourself for about an hour.

Confidentiality: The interviews will be recorded on tape. The tape will be typed out by a secretary. The name of the person(s) in the interview will not be recorded on the tape or the paper. Instead a number will be given to that interview. This number, or a fake name, will be used on anything that gets written about the interview. Only three people will know the name of the person on the tape. These are the person who did the interview, the person who was the observer, and the typist who types from the tape. All these people will sign an Oath of Confidentiality in whish they promise to not give your name to anyone. All of the information that has the person's name on it will be locked up as will the typed information.

Interviews will be done at the family's home or the researcher's office when the family wishes. It is possible that people at the researcher's office will know that you took part in this research study if the interview is held there. But, they will not know what you said.

All information will remain confidential except where the law or professional obligations require reporting such as in cases of abuse of children.

Benefits: This study may not have any direct benefits for you. But, it is hoped that trough this study the experiences of families who have lost a child and are mourning will be better understood. Many people who take part in such studies report that telling their story has been helpful and the chance to help others in this situation is rewarding.

Risks: It is not expected that being in this study will harm you. But, painful memories may resurface either during or after the interviews. The researcher will talk to you about these feelings and help you find any help you need as well as give you a list of some counseling resources in your community.

Withdrawal from the Study: Even after you have agreed to take part in this study you can leave it at any time. I will ask you if you want to do another interview each time we meet. You can also decide after the first or second interview that you do not want what you said to be used in the study. The researchers then cannot use what you said in direct quotes. But because of the nature of this study what you said can not be removed after three weeks.

Use of your Information: This study is being done for a Doctoral dissertation. This study is not being paid for by the University of Alberta, Stollery Children's Hospital, Alberta Children's Hospital, The Compassionate Friends. What you say in the interview will not cause you to lose any services from the organizations with which you are involved. The researcher is a student at the University of Alberta. What everyone says will be made into a report. If you want, a short version of this report will be mailed to you.

I will keep the data as it might be used in another study in the future to answer other questions on family mourning. If that happens, the researcher of the new study will obtain ethics approval.

What is learned from these interviews will be presented at conferences for professionals working with people in grief. It will also be published in professional journals and may be published in magazines or a book.

Rights as Participants: As participants your family has the following rights:

1) You do not have to give any information you are uncomfortable giving especially that which you feel will be difficult for other family members to hear.
2) You may refuse to answer any question during the study or stop the study at any time.

3) You may refuse to be audio taped.
4) If for any reason any member wishes to withdraw from the study, he or she may do so. Information provided by your family may be withdrawn up to 3 weeks after the interview.
5) You may call the researcher with any questions or concerns you may have about the study.

Study Involvement of Participants: As participants your family will be involved in the following ways:

1) You will be interviewed together twice for up to 90 minutes per session.
2) You will be interviewed individually for up to two hours each.
3) You may be contacted to discuss the results of the research study. This interview will be up to 30 minutes and may be by phone or in person. If you wish to have a copy of the results, a copy will be given to you.

If you have any concerns about this study, you can contact Georgie Jarvis, AFHE Research Ethics Board Administrator, 2-14 Ag/For Centre, University of Alberta, 492-8126 (georgie.jarvis@ualberta.ca).

APPENDIX D

CONSENT FORM (ADULTS)

Title of Project: *Family mourning: The experience of families when a child dies*

Investigators:

Co-Primary Investigator	Co-Primary Investigator	Co-Investigator
Priscilla M. Koop RN PhD	Judith Spiers RN PhD	Margaret A. deJong-Berg MSW)
Associate professor	Assistant professor	Graduate Student
Faculty of Nursing	Faculty of Nursing	Department of Human Ecology
3rd floor CSB	3rd floor CSB	3rd floor Human Ecology Building
University of Alberta	University of Alberta	University of Alberta
Phone: 492-2962	Phone: 492-9821	Phone: 492-7789 (B) 452-0594 (H)
FAX: 492-2551	FAX: 492-2551	FAX: 492-2551

Consent: Please circle your answers:

Do you consent to being audio-taped?	YES	NO
Do you understand that you have been asked to be in a research study?	YES	NO
Have you read and received a copy of the attached Information Sheet?	YES	NO
Do you understand the benefits and risks involved in taking part in this research study?	YES	NO
Have you had an opportunity to ask questions and discuss this study?	YES	NO
Do you understand that you can quit taking part in this study at any time? You do not have to say why and it will not affect the services you are receiving.	YES	NO
Has confidentiality been explained to you?	YES	NO
Do you understand who will be able to see or hear what you said?	YES	NO
Do you understand that people at the University of Alberta may know that you participated in this study, but they will not know what you said?	YES	NO
Do you know what your information will be used for?	YES	NO
Do you give us permission to use your data for the purposes specified?	YES	NO

Date________________ Participant's signature______________________

Researcher's signature________________________

APPENDIX D

CONSENT FORM (CHILDREN TO BE SIGNED BY PARENT)

Title of Project: *Family mourning: The experience of families when a child dies*

Investigators:

Co-Primary Investigator	**Co-Primary Investigator**	**Co-Investigator**
Priscilla M. Koop RN PhD	Judith Spiers RN PhD	Margaret A. deJong-Berg MSW
Associate professor	Assistant professor	Graduate Student
Faculty of Nursing	Faculty of Nursing	Department of Human Ecology
3rd floor CSB	3rd floor CSB	3rd floor Human Ecology Building
University of Alberta	University of Alberta	University of Alberta
Phone: 492-2962	Phone: 492-9821	Phone: 492-7789 (B) 452-0594 (H)
FAX: 492-2551	FAX: 492-2551	FAX: 492-2551

Consent: Please circle your answers:

Do you consent to your child being audio-taped?	YES	NO
Do you understand that your child has been asked to be in a research study?	YES	NO
Have you read and received a copy of the attached Information Sheet?	YES	NO
Do you understand the benefits and risks to your child's involvement in taking part in this research study?	YES	NO
Have you had an opportunity to ask questions and discuss this study?	YES	NO
Do you understand that your child can quit taking part in this study at any time? They do not have to say why and it will not affect the services you are receiving.	YES	NO
Has confidentiality been explained to you?	YES	NO
Do you understand who will be able to see or hear what your child has said?	YES	NO
Do you understand that people at the University of Alberta may know that your child has participated in this study, but they will not know what he/she said?	YES	NO
Do you know what your child's information will be used for?	YES	NO
Do you give us permission to use your child's data for the purposes specified?	YES	NO

Date________________ Participant's signature______________________

Researcher's signature______________________

APPENDIX D

INFORMATION SHEET AND ASSENT FORM FOR CHILDREN (ages 12 to 18)

Study title: *Family mourning: The experience of families when a child dies*

I am a university student talking to families when a child has died. I want to hear what happened for your family as you lived each day since your brother or sister died. Your ideas are important to me. I will record our talk if you say it is OK.
If you decide to be a part of the study, we will meet together with your family. I will also talk with you alone, I have some questions for you and your family. I will not use your real name in the report of my study.

Researchers :

Co-Primary Investigator	**Co-Primary Investigator**	**Co-Investigator**
Priscilla M. Koop RN PhD	Judith Spiers RN PhD	Margaret A. deJong-Berg MSW
Associate professor	Assistant professor	Graduate Student
Faculty of Nursing	Faculty of Nursing	Department of Human Ecology
		3rd floor Human
3rd floor CSB	3rd floor CSB	Ecology Building
University of Alberta	University of Alberta	University of Alberta
Phone: 492-2962	Phone: 492-9821	Phone: 492-7789 (B) 452-0594 (H)
FAX: 492-2551	FAX: 492-2551	FAX: 492-2551

As participants you have the following rights:

1) You don't have to talk about anything you don't want to.
2) You may stop our talk at any time.
3) You may ask to quit at any time by telling Marge or asking your family to tell her.
4) You may call the researcher with any questions or concerns you may have about the study.

As participants your family will be involved in the following ways:

1) We will meet together with your family twice for up to 90 minutes.
2) I will be talking with you alone for up to one hour.
3) The meetings will be at your home or my office which ever is best for you and your family.
4) All meetings will be tape recorded and a written record made.
5) A code will be used in place of your to protect your identity.

Risks and Benefits to the Participants:

Things that you or you family tell me could bring back some sad memories. Please tell me if this happens for you. Many people find that they like to tell their story and often these stories are helpful to other families who experience the death of a child.

Please read the following and sign in the front of the researcher:

I, ________________________________, (Please print your name) agree to be part of this study. I understand what the study is about and I may stop taking part at any time from this study. I have read the above information and have my own copy.

___ I am aware that all my interviews will be tape (audio) recorded and agree to this recording.

Date_________________ Participant's signature_______________________

Researcher's signature______________________________

APPENDIX D

CONSENT FOR PHOTOGRAPHY AND USE OF AUDIO RECORDING

Study title: *Family mourning: The experience of families when a child dies*
Researchers:

Co-Primary Investigator	**Co-Primary Investigator**	**Co-Investigator**
Priscilla M. Koop RN PhD	Judith Spiers RN PhD	Margaret A. deJong-Berg MSW
Associate professor	Assistant professor	Graduate Student
Faculty of Nursing	Faculty of Nursing	Department of Human Ecology
3rd floor CSB	3rd floor CSB	3rd floor Human Ecology Building
University of Alberta	University of Alberta	University of Alberta
Phone: 492-2962	Phone: 492-9821	Phone: 492-7789 (B) 452-0594 (H)
FAX: 492-2551	FAX: 492-2551	FAX: 492-2551

I, ________________________________, give Margret deJong-Berg permission

1. to take photos or copy photos for her study. I understand that these images may be used for educational demonstrations, displays, and publications.

Please circle: yes no

2. to use audio clips/quotes of my interview for educational presentations.

Please circle: yes no

For further information relating to the creation, use and disposal of these recordings and images, contact: Georgie Jarvis, AFHE Research Ethics Board Administrator, 2-14 Ag/For Centre, University of Alberta, 492-8126 (georgie.jarvis@ualberta.ca).

Participant's Name________________________________ Date________________

Please Print

Signature____

Researcher's signature____________________________

APPENDIX E

INVITATION TO PARTICIPATE

BEREAVED PARENTS RECRUITED FROM CHILDREN'S HOSPITALS

(sent on hospital letterhead)

Dear (family name):

I invite you to take part in a study on family mourning. This study, *Family mourning: The experience of families when a child dies*, is being done by Marge de Jong-Berg a graduate student at the University of Alberta, Department of Human Ecology (Family Studies). This study will investigate the experience of families as they live with the loss of a child. An information sheet on the details of this study with contact information is enclosed. This study has been approved by the University of Alberta Research Ethics Committee (file # ------).

This study is voluntary. It is not part of the (Name of Children's Hospital) bereavement program. We do, however, support this research. Your decision to take part in it or not will have no effect on the services you receive from the (Name of Children's Hospital). If you do not wish to take part you will still receive our Bereavement Follow-up Program at the (Name of Children's Hospital).

If you have any questions or concerns, please call me at (telephone number).

Sincerely,

(NAME)
Grief Counselor, Pediatric Palliative Care

APPENDICES F

FOR USE BY PARTICIPANTS RECRUITED FROM CHILDREN'S HOSPITALS

STUDY INFORMATION SHEET
CONSENT FORM (ADULTS)
CONSENT FORM (CHILDREN TO BE SIGNED BY PARENT)
INFORMATION SHEET AND ASSENT FORM FOR CHILDREN (ages 12 to 18)
CONSENT FOR PHOTOGRAPHY AND USE OF AUDIO RECORDING

APPENDIX F

STUDY INFORMATION SHEET

Study title: *Family mourning: The experience of families when a child dies*

Researchers:
Priscilla M. Koop RN PhD, University of Alberta, Associate professor, 492-2962

Judith Spiers RN PhD, University of Alberta, Assistant professor, 492-9821

Margaret (Marge) A. deJong-Berg MSW, University of Alberta, Graduate Student, 492-7789, email: maberg@ualberta.ca

Purpose: The purpose of this study is to describe and explore how families mourn the death of a child in their family.

Methods: Marge will arrange a time to meet and talk to you and your family about your experiences when your child died. Marge will meet with your family, including children over 12 years old, two or three times and with you (and each member of your family) as an individual once. These interviews will be audio-taped. Marge would be happy to see a photo of your child or some of the special things you have to remember her/him. Marge may ask to take a picture of these things. Together with your family Marge will talk to you about what family is to you and how the loss of your child has affected your family. Your family will work together to draw a map of your family and describe your family. You will be asked to allow an observer to attend the sessions with your family. This observer is a social worker who understands families who are grieving. The observer will make notes during the session such as who is talking and when. You can say no to having this observer at the family sessions. If you do special things like going to his/her grave as a family or have remembrance ceremonies, Marge may ask to observe these events, but you can say no to that request.

In the interview with just you, Marge will talk about the feelings you have had since your child died and how what your family did during this time affected your grief. Your children may want to tell their story in drawings or writing to relate their experience.

You can choose first to talk with Marge alone or as a family, whichever you think is best. If you and Marge talk alone first, what you say will just be between us. Marge will not tell these things to your family unless you give her permission.

These interviews will take place in your home or at the researchers' office, whichever is best for you. If you come to Marge's office the cost of parking will be paid for you. The family sessions will take about 90 minutes the first time and 60 minutes the second time. If you or any member of your family becomes too tired after drawing the family map and showing Marge your photos and mementos to continue, Marge will arrange another time for you to finish the interview as a family. Marge will talk with you by yourself for about an hour. Sometimes Marge may need to phone you to clarify the information you provide in your interview.

Confidentiality: The interviews will be recorded on tape. The tape will be typed out by a typist. The name of the person(s) in the interview will not be recorded on the typed paper of the interview (transcript). Instead a number and a family name that is not your own will be given to that interview. This number or name will be used on anything that gets written about the interview. Only three people will know the name of the person on the tape. These are Marge, the person who was the observer, and the typist who types from the tape. All these people will sign an Oath of Confidentiality in which they promise to not give your name or discuss what you said with anyone. All of the information that has your name on it will be locked up separately from the typed information. Interviews will be done at your home or Marge's office whichever you prefer. There is a slight chance that if the interview is held at Marge's office and you know someone there that they will know that you took part in this research study. But, they will not know what you said. All information will be held private except when professional codes of ethics or legislation require. It is the law that anything you say in the interview about a child being abused has to be reported to Alberta Child and Family Services.

Benefits: This study may not have any direct benefits for you. But, it is hoped that through this study the experiences of families who have lost a child and are mourning will be better understood. Many people who take part in such studies report that telling their story is helpful and the chance to help others in this situation is rewarding.

Risks: It is not expected that being in this study will harm you. But, painful memories may resurface either during or after the interviews. If this happens to you, Marge will talk to you about these feelings and help you find any help you need. Marge will give you a list of some counseling resources in your community.

Withdrawal from the Study: Even after you have agreed to take part in this study you can leave it at any time. You can also decide after the first or second interview that you do not want what you said to be used in the study. Then Marge will not use what you said in direct quotes. But because of the nature of this study it may not be possible to remove the effect of your presence on what other family members said. It is not possible to remove your ideas from the family interview after two weeks.

Use of your Information: This study is being done for a doctoral dissertation. This study is not being paid for by the University of Alberta, Stollery Children's Hospital, Alberta Children's Hospital, or The Compassionate Friends. What you say in the interview will not cause you to lose any services from the organizations with which you are involved. Marge is a student at the University of Alberta. What everyone says will be made into a report. If you want, a short version of this report will be mailed it to you.

Marge will keep the audio tapes and transcribed data in the Faculty of Nursing as it might be used in another study in the future to answer other questions on family mourning. Scanned and photographed memento data will not be available to future researchers except where already public through publication and presentation. If that happens, the researcher of the new study will obtain ethics approval. What is learned from these interviews will be presented at conferences for professionals working with people in grief. It will also be published in professional journals and may be published in magazines or a book.

Rights as Participants: As a participant, you have the following rights:

6) You do not have to give any information you are uncomfortable giving. Especially in the family interview you may not want to share information which you feel will be difficult for other family members to hear.

7) All information given in your individual interview will be held confidential by Marge. However, you may choose to repeat it in the family interview.
8) You may refuse to answer any question during the study or stop the study at any time. You may refuse any requests of the researcher, including but not limited to attendance at the remembrance ceremonies or gravesite visits.
9) You may refuse to be audio taped.
10) If for any reason you wish to withdraw from the study, you may do so. Information provided by you may be withdrawn up to 2 weeks after the interview.
11) You may call Marge or her supervisors (listed above) with any questions or concerns you may have about the study.

Study Involvement of Participants: As a participant you will be involved in the following ways:

4) You will be interviewed together with your family twice for up to 90 minutes per session. Sometimes you or a member of your family may choose to divide the first family interview into 2 sessions. Then 3 sessions will be held.
5) You will be interviewed individually for up to one hour.
6) You may be contacted to clarify what you said in your individual interview. This interview will be up to 30 minutes and may be by phone or in person.
7) If you wish to have a copy of the results, a copy will be given to you.

If you have any concerns about this study, you can contact Helen Steinke, AFHE Research Ethics Board Administrator, 2-14 Ag/For Centre, University of Alberta, 492-8126 (email:helen.steinke@ualberta.ca)

APPENDIX F

CONSENT FORM (ADULTS)

Title of Project: *Family mourning: The experience of families when a child dies*

Investigators:

Priscilla M. Koop RN PhD, University of Alberta, Associate professor, 492-2962

Judith Spiers RN PhD, University of Alberta, Assistant professor, 492-9821

Margaret (Marge) A. deJong-Berg MSW, University of Alberta, Graduate Student, 492-7789, email: maberg@ualberta.ca

Consent: Please circle your answers:

Do you consent to being audio-taped?	YES	NO
Do you understand that you have been asked to be in a research study?	YES	NO
Have you read and received a copy of the attached Information Sheet?	YES	NO
Do you understand the benefits and risks involved in taking part in this research study?	YES	NO
Have you had an opportunity to ask questions and discuss this study?	YES	NO
Do you understand that you can quit taking part in this study at any time? You do not have to say why and it will not affect the services you are receiving.	YES	NO
Has confidentiality been explained to you?	YES	NO
Do you understand who will be able to see or hear what you said?	YES	NO
Do you know what your information will be used for?	YES	NO
Do you give us permission to use your data for the purposes specified?	YES	NO
Do you give us permission to use your data for future studies (secondary analysis)? Note that ethical approval will be sought.	YES	NO

Date_________________ Participant's signature_______________________

Researcher's signature__________________________

APPENDIX F

CONSENT FORM (CHILDREN TO BE SIGNED BY PARENT)

Title of Project: *Family mourning: The experience of families when a child dies*

Investigators:
Priscilla M. Koop RN PhD, University of Alberta, Associate professor, 492-2962

Judith Spiers RN PhD, University of Alberta, Assistant professor, 492-9821

Margaret (Marge) A. deJong-Berg MSW, University of Alberta, Graduate Student, 492-7789, email: maberg@ualberta.ca

Consent: Please circle your answers:

Do you consent to your child being audio-taped?	YES	NO
Do you understand that your child has been asked to be in a research study?	YES	NO
Have you read and received a copy of the attached Information Sheet?	YES	NO
Do you understand the benefits and risks to your child's involvement in taking part in this research study?	YES	NO
Have you had an opportunity to ask questions and discuss this study?	YES	NO
Do you understand that your child can quit taking part in this study at any time? They do not have to say why and it will not affect the services you are receiving.	YES	NO
Has confidentiality been explained to you?	YES	NO
Do you understand who will be able to see or hear what your child has said?	YES	NO
Do you know what your child's information will be used for?	YES	NO
Do you give us permission to use your child's data for the purposes specified?	YES	NO
Do you give us permission to use your child's data for further studies (secondary analysis)? Note: ethical approval for further studies will be sought.	YES	NO

Date__________________ Participant's signature_________________________

Researcher's signature____________________________

APPENDIX F

INFORMATION SHEET AND ASSENT FORM FOR CHILDREN (ages 12 to 18)

Study title: *Family mourning: The experience of families when a child dies*

Researchers:

Priscilla M. Koop RN PhD, University of Alberta, Associate professor, 492-2962

Judith Spiers RN PhD, University of Alberta, Assistant professor, 492-9821

Margaret (Marge) A. deJong-Berg MSW, University of Alberta, Graduate Student, 492-7789, email: maberg@ualberta.ca

My name is Marge. I am a university student talking to families when a child has died in their family. I want to hear what happened for your family as you lived each day since your brother or sister died. Your ideas are important to me. I will tape record our talk if you say it is OK.

If you decide to be a part of the study, we will meet together with your family. I will also talk with you alone. I have some questions for you and your family. I will not use your real name in the report of my study.

As a participant you have the following rights:

1) You don't have to talk about anything you don't want to.
2) You may stop our talk at any time.
3) You may ask to quit at any time by telling Marge or asking your family to tell her.
4) You may call any of the researchers listed above with any questions or concerns you may have about the study.
5) You may refuse to have your picture taken and used by Marge in written and oral reports.

As participants your family will be involved in the following ways:

6) We will meet together with your family twice for up to 90 minutes.
7) I will be talking with you alone for up to one hour.
8) The meetings will be at your home or my office which ever is best for you and your family.
9) All meetings will be tape recorded and a written record made.
10) A code will be used in place of your name to protect your identity.

Risks and Benefits to the Participants:

Things that you or you family tell Marge could bring back some sad memories. Please tell her if this happens for you. Many people find that they like to tell their story. These stories are helpful to people working with other families who experience the death of a child.

Please read the following and sign in the front of Marge:

I, ________________________________, (Please print your name) agree to be part of this study. I understand what the study is about. I may stop taking part in this study at any time. I have read the above information and have my own copy.

___ I am aware that all my interviews will be tape (audio) recorded and agree to this recording.

Date________________ Participant's signature______________________

Researcher's signature_____________________________

APPENDIX F

CONSENT FOR PHOTOGRAPHY AND/OR USE OF AUDIO RECORDING

(to be completed by children and adults)

Study title: *Family mourning: The experience of families when a child dies*

Researchers:

Priscilla M. Koop RN PhD, University of Alberta, Associate professor, 492-2962

Judith Spiers RN PhD, University of Alberta, Assistant professor, 492-9821

Margaret (Marge) A. deJong-Berg MSW, University of Alberta, Graduate Student, 492-7789, email: maberg@ualberta.ca

I, (print name)________________________________, give Margaret deJong-Berg permission to:

1. take photos or copy photos for her study. I understand that these images may be used for educational demonstrations, displays, and publications.

Please circle: yes no

and/or

2. use audio clips of my interview for educational presentations.

Please circle: yes no

For further information relating to the creation, use and disposal of these recordings and images, contact: Helen Steinke, AFHE Research Ethics Board Administrator, 2-14 Ag/For Centre, University of Alberta, 492-8126 (helen.steinke@ualberta.ca).

Participant's Signature ________________________________

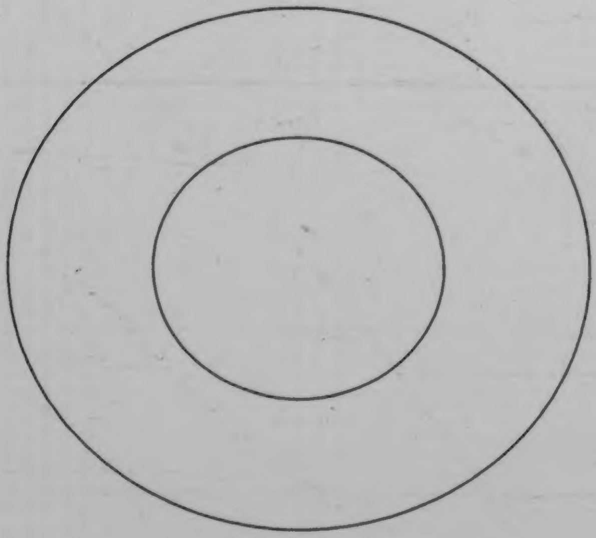
Date________________

Researcher's Signature ________________________________

APPENDIX G

CIRCLE OF PEOPLE RESOURCES

INSTRUCTIONS: In the innermost circle put the people (by relationship to you) who provided you with the most support during your bereavement. In the outer circle put those who were your second line of defense. Add more circles as you need to show others who provided support indicating the level of support they gave by the circle they are in (i.e. the outermost circle would indicate those who provided the least level of support to you but were still supportive). Circle those people you consider family.



APPENDIX H

FAMILY INTERVIEW QUESTIONS AND PROBES

1. Tell me about your family?
    Probes: Who are the members of your family?
        Have you had any changes since (name) died such as a move, a changing job, further deaths?

2. Tell me briefly about the circumstances of (name) death?
    Probes: If the child died from illness, was he/she always sick?
        Were you present at the death?
        Who told you (name) had died?
        If the child died in an accident, was he/she the only one who died/was hurt?

3. What was your family like before (name) died?
    Probes: What was the average day like for you?
        What things did you do as a family to have fun? To celebrate special occasions?
        Tell me about your family roles, who did what?
        What will your family rules? Who set the rules?

4. What is your family like now following (name) death?
    Probes: What is the average day like now?
        How do you have fun now?
        Do you have special ways to remember (name)?
        Have rules/roles changed in your family?
        Has communication changed in your family?

5. What would be one thing you want others who are new to the loss of a child (or brother/sister) to know about this experience?

APPENDIX I

RESOURCES FOR BEREAVEMENT COUNSELLING

Name, grief counselor Children's Hospital Pediatric Palliative Care	phone number

-will provide counseling free of charge to family members from this study

Other resources

Support Network	phone number

-offers a drop-in single session counseling service, phone for details and hours

Sliding scale of fees

Catholic Social Services	phone number
Family Centre	phone number
City Bereavement Centre	phone number

-a nondenominational service of Jewish Family Services, offers bereavement groups

Pastoral Counseling Group	phone number

Full fee (many companies have employee assistance programs (EAP) that will assist with the cost of counseling)

Roster of bereavement counselors available through:

College of Psychologists	phone number
College of Social Workers	phone number
Please phone researcher for further resources	492-7789

APPENDIX J

INDIVIDUAL INTERVIEW QUESTIONS AND PROBES

1. Could you tell me what these terms mean to you, grief, mourning, bereavement?

2. Could you tell me what it was like for you when (name) died?
   Probes: What did you feel when (name) died?
   How did those feelings change?
   How did you go about your work/school life?
   Did you talk about your grief? To whom?
   What things did you do to deal with your grief?
   What was it like for you at home?

3. How do you think your family has influenced/ been influenced by your individual experience of grief?'
   Probes: Have other family members made comments to you/done things that you have found helpful/hurtful?
   Have you felt the need to help anyone else with their grief?
   Does your family do special things to remember (name)? Do take part in these things

4. Is there anything else you want me to understand of your experience that we have not talked about?